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FEMINISM AND DISABILITY

Jenny Morris

This article has its roots in a series of seminars on *Researching Physical Disability*, funded by the Joseph Rowntree Foundation. As a feminist I should have felt a sense of unity with other feminist researchers attending the seminars and there certainly were occasions when a sense of sisterly solidarity prevailed against the way that some of the male participants operated. As a disabled woman, however, I felt a deep sense of alienation from the nondisabled feminists present and anger that there seemed to be an assumption that they were 'on the same side' as me. This alienation and anger comes from the failure of feminism to integrate the concerns of disabled women into its theory, methodology, research and politics.

My sense of alienation also extends to *Feminist Review* for, looking at my copies of back issues of this journal, the only reference to disability is a book review which I myself wrote in 1989. (Nasa Begum's article *Disabled Women and the Feminist Agenda*, was published in *FR*40 after this article was written.) My confidence that this is an appropriate forum for this article falters. Yet I believe that feminism itself is the poorer for its failure to address the concerns of disabled women. Coming at it from another angle, I also believe that feminist theory and methodology has a major contribution to make to disability research.

The alienation and anger that I feel stem from two characteristics of feminism: firstly, the way in which disability is generally invisible in terms of feminism's mainstream agenda; secondly, the way in which, when disability *is* a subject for research by feminists, the researchers fail to take on the subjective reality of disabled people, instead objectifying us so that the research is alienated from our experience.

Missing us out

There have been two stages to the development of feminism in an academic context over the last twenty years or so. The first was that of

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'adding women in' to the previously male-dominated view of the world. This produced some revealing studies in a number of different disciplines, but it was the second stage that was more revolutionary. Feminists found that, rather than just adding women to the subject matter of research, theories and methodologies had to be fundamentally challenged for existing models and paradigms were inadequate to explain women's (or indeed men's) realities.

In so doing, feminists not only asserted that the personal, subjective experience of women was a legitimate area of research but that how this research was done had to be revolutionized. They went on to develop new paradigms, theories and, finally, a new philosophy which illustrated that feminism is not just about the study of women but is an entirely new way of looking at the world.

The most recent developments in feminist thought have focused on a recognition of the experiences of different groups of women and the relationship between gender and other forms of oppression. Elizabeth Spelman, amongst other feminist philosophers, has argued in her book, *Inessential Woman* (1990) that feminism's assertion of what women have in common has almost always been a description of white, middle-class women and that when other groups of women are considered they tend to be 'added on' as subjects of research and theorizing. White, middle-class women's experiences have been taken as the norm and other women's experiences have been treated as 'different', as the subject of particular study and analysis. Thus, white, middle-class women's reality is the basis of general theory and analysis (in the same way that men's reality was), and the reality of other groups of women is treated as particular, as separate from the general.

Spelman writes, for example, 'Most philosophical accounts of "man's nature" are not about women at all. But neither are most feminist accounts of "woman's nature", or "women's experiences" about all women. There are startling parallels between what feminists find disappointing and insulting in Western philosophical thought and what many women have found troubling in much of Western feminism' (Spelman, 1990: 6). Such a recognition has (potentially) as radical an effect on feminist thought as feminism itself has had on world views dominated by men and men's experiences.

Yet there are two groups of women who are missing from Spelman's analysis. In identifying that 'working-class women, lesbian women, Jewish women and women of colour' have been considered as 'inessential' within feminist philosophy, Spelman has – in common with most nondisabled feminists – left out two important groups, namely older women and disabled women. Disability and old age are aspects of identity with which gender is very much entwined but they are identities which have been almost entirely ignored by feminists.

Feminist theory has been broadened, and refined, by the placing of the issues of class and race at the heart of feminism as a philosophy and as explanation. But the issues of disability and old age are either not considered at all, or dismissed in the way that Caroline Ramazanoglu does when she justifies her failure to incorporate disabled and older women into her analysis. She writes 'while these are crucial areas of oppression for many women, they take different forms in different cultures, and so are difficult to generalise about. They are also forms of difference which could be transformed by changes in consciousness' (Ramazanoglu 1989: 95). These are really flimsy arguments. Racism also takes different forms in different cultures yet recent feminist analysis has, quite rightly, argued that Black women's experiences and interests must be placed at the heart of feminist research and theory. Her second statement is an extraordinary denial of the socio-economic base of the oppression which older people and disabled people experience – we might as well say that racism can be eradicated by compulsory antiracism training.

The fact that disability has not been integrated into feminist theory arises from one of the most significant problems with feminism's premise that 'the personal is political'. As Charlotte Bunch acknowledges in her exploration of divisions and coalitions amongst feminists from the point of view of lesbians, women have often failed to take account of different experiences and interests.

> In looking at diversity among women, we see one of the weaknesses of the feminist concept that the personal is political. It is valid that each woman begins from her personal experiences and it is important to see how these are political. But we must also recognize that our personal experiences are shaped by the culture with all its prejudices. We cannot therefore depend on our perceptions alone as the basis for political analysis and action – much less for coalition. Feminists must stretch beyond, challenging the limits of our own personal experiences by learning from the diversity of women's lives (Bunch, 1988: 290).

Disabled people – men and women – have little opportunity to portray our own experiences within the general culture – or within radical political movements. Our experience is isolated, individualized; the definitions which society places on us centre on nondisabled people's judgements of individual capacities and personalities and are dominated by what disability means to nondisabled people. This lack of a voice, of the representation of our subjective reality, means that it is difficult for nondisabled feminists to incorporate our reality into their research, their theories, unless it is in terms of the way the nondisabled world sees us.

This does not mean that the experience of disability and old age should be 'added on' to existing feminist theory. Integrating these two aspects of identity into feminist thought will be just as revolutionary as feminism's political and theoretical challenge to the way that the experience of the white male was taken as representative of general human experience. Indeed feminism's challenge must remain incomplete while it excludes two such important aspects of human experience and modes of social and economic oppression.

Research as alienation

Patricia Hill Collins, writing about the development of Black feminist thought, echoes a general concern of feminism when she says, 'Groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others' (Hill Collins, 1990: 6). Feminism's central task has been to make women's standpoint known to both ourselves and to others. In an academic context, this is not so much an ideological position on women's oppression; rather it is, as Dorothy Smith says, a method 'that, at the outset of inquiry, creates the space for an absent subject, and an absent experience, that is to be filled with the presence and spoken experience of actual women speaking of and in the actualities of their everyday worlds' (Smith, 1988: 107).

Feminist research over the last twenty years has been characterized by an attempt to 'create space for an absent subject', in contrast to the way in which women have frequently been objectified by and thus alienated from 'research on women'. Liz Stanley identifies three factors which distinguish 'unalienated knowledge' in feminist terms:

> – the researcher/theorist is grounded as an actual person in a concrete setting;
> – understanding and theorising are located and treated as material activities and not as unanalysable metaphysical 'transcendent' ones different in kind from those of 'mere people'; and
> –the 'act of knowing' is examined as the crucial determiner of 'what is known' (Stanley, 1990: 12)

If we apply these principles to feminist research concerning disability, however, we see that such research is in fact alienated knowledge as far as disabled people are concerned. This is because the researcher/theorist has not grounded herself as a nondisabled person holding certain cultural assumptions about disability; because the understanding and theorizing have not been treated as taking place in the context of an unequal relationship between nondisabled people and disabled people; and because the 'act of knowing', which in this case is predicated on the social meaning of disability, has not been examined as the crucial determiner of 'what is known'.

Feminist research on informal carers is a prime example of the production of alienated research from the point of view of disabled people. Most of this research explicitly separates out nondisabled women from disabled women. Gillian Dalley's *Ideologies of Caring* (1988), for example, refers to 'women and dependent people' as if they are two completely separate groups, whose interests, what is more, are in conflict. She introduces her book by saying, 'This book is about dependent people and the women who usually care for them' (Dalley, 1988: 1). This separation of 'women' from disabled and older people is evident in most of the feminist research on caring and has major implications for the questions and issues which feminists consider important. Finch and Groves (1983), for example, identified that the equal opportunity issues around community care were those concerning the sexual division of labour between men and women as carers. In none of the pieces of research is there any analysis of equal opportunity issues for disabled and older women.

This separating out of disabled and older women from the category of 'women' comes about because of a failure of the feminist researchers concerned to identify with the subjective experience of those who need some form of care. The principle of 'the personal is political' is applied to carers but not to the cared for. This general tendency is articulated by Clare Ungerson's account of why the issue of caring is of personal significance to her. She writes

> My interest in carers and the work that they do arises out of my own biography. The fact that my mother was a carer and looked after my grandmother in our home until my grandmother's death when I was 14 combines with the knowledge that, as an only daughter, my future contains the distinct possibility that I will sooner or later become a carer myself (Ungerson, 1987: 2).

Lois Keith, a disabled feminist, commented on Ungerson's inability to see *herself* (and not just her mother) as potentially a person who needs physical care.

> Most of us can imagine being responsible for someone weaker than ourselves, even if we hope this won't happen. It is certainly easier to see ourselves as being needed, than to imagine ourselves as dependent on our partner, parents or children for some of our most basic needs (Keith, 1990).

Ungerson's failure to identify with the interests and experiences of those who need care is then carried over into her feminist analysis. Thus she writes, 'The second set of reasons for writing this book is that it accords with and is fed by my own commitment to women-centred issues and to feminism'. She goes on to identify what are the 'women-centred' issues around community care, writing

> It has almost reached the dimensions of banality to claim that most carers are women. Nevertheless, given the accuracy of that statement, it seems to me necessary to explore the full implications of the fact. If most carers are women, do women carers feel that what they do is particularly compatible with their female identity? Do men carers feel emasculated? How do women carers feel about caring for men? How do men carers feel about caring for women? There is more to a feminist approach to knowledge than in the documentation of the role of women in a set of social processes; while this is important, it is also necessary (and even exciting) to use issues of sex and gender to illuminate those very social processes. The topics discussed in this book are always considered from a gendered perspective; in other words, I have tried throughout to think

> about the issues by asking the question, do sex and gender make a difference? (Ungerson, 1987: 2).

Like most feminists who have written on this subject, Ungerson fails to incorporate into her analysis the fact that, not only are most carers women (although, in fact, not such a large proportion as feminists have assumed), but so are most of 'the cared for'. Her analysis of social processes involved in the issue of caring must remain incomplete while she considers only one part of the caring relationship and, far from being exciting, research such as hers is profoundly depressing from the point of view of disabled and older women who are yet again marginalized – but this time by those who proclaim their commitment to 'women-centred issues'.

Feminist research on carers is a valuable application of the principle 'the personal is political' and I do not underestimate the importance of the higher public profile of the needs of carers which this research has helped to bring about. However, the failure to include the subjective experience of disabled and older people has resulted in a dilemma being posed between 'care in the community' or residential care. Feminists such as Janet Finch and Gillian Dalley have then come down in favour of residential care for older and disabled people on the grounds that this is the only way to prevent the exploitation of women as informal carers. Finch writes, 'On balance it seems to me that the residential route is the only one which ultimately will offer us a way out of the impasse of caring' (Finch, 1984: 16). The term 'us' in this context quite obviously does not encompass the interests of disabled women so Finch and others have been able to ignore the opposition of disabled people and their organizations to institutional 'care'. (For a fuller discussion of feminist research on carers see the chapter on 'Feminist research and community care' in Morris, 1991.)

Disability – a challenge for feminism

Disability is an important issue for women but the subject of 'disabled women' should not be tacked on as a 'free-standing' research subject bearing no relationship to other research areas in which feminists are engaged. In my own research, I have recently come across three examples of oppression experienced by disabled women where gender issues intermesh with disability, although in different ways:

- the rape of a young disabled woman by an ambulance attendant while she was being taken home from a residential college with a broken arm;
- the recording, by a male social worker, in the case notes of a disabled client that he thought he had discovered her masturbating and the conclusions that he drew from this about her personality;
- a policeman and social worker waiting in a hospital corridor for a

> disabled woman to give birth at which point they removed her baby from her under a Place of Safety Order on the grounds that her physical disability prevented her from looking after the child.

These incidents are all concerned with violation of one kind or another and they all take place in the context of both unequal power relationships and oppressive ideologies. All three examples illustrate different ways in which the oppression experienced by women and by disabled people intermesh. What is more interesting to me, however, is whether the experience of the women described above appears on the main agenda of nondisabled feminist researchers – or is it, at best, tacked on as a supplementary issue, on the assumption that disabled women's experience is separate from that of nondisabled women? My challenge to feminists, therefore, is that they need to ask themselves whether these experiences of oppression are only of interest to disabled women.

I would also argue that it is not very helpful to talk about disabled women experiencing a 'double disadvantage'. Images of disadvantage are such an important part of the experience of oppression that research which seeks to further the interests of 'the researched' must consistently challenge them. Therein lies one of the problems with examining the relationship between gender and disability, race and disability in terms of 'double disadvantage'. The research can itself be part of the images of disadvantage.

Feminist research and theorizing which is concerned with nondisabled women has often been driven by a sense of outrage at the consequences of women's powerlessness in relation to men. Whether it is domestic violence, rape, unequal pay or sex-role stereotyping in children's books, such research refuses to see women as passive victims and the motivating anger is an important part of the empowerment process. The focus has very much been on men and social institutions as the problem. In contrast, there is a tendency when describing the 'double disadvantage' that disabled women experience to shift attention away from nondisabled people and social institutions as being the problem and onto disabled women as passive victims of oppression.

If disability research is to be unalienated research then it must be part of disabled people's struggle to take over ownership of the definition of oppression, of the translation of their subjective reality. As Alice Walker writes – 'In my own work I write not only what I want to read. . . . I write all the things I should have been able to read'. I don't think that I, or many other disabled women, want to read of nondisabled researchers analysing how awful our lives are because we 'suffer from' two modes of oppression.

If feminists are to concern themselves with disability research, such research must aim to empower disabled people. Nondisabled researchers have to start by questioning their own attitudes to disability. For example, why does Caroline Ramazanoglu dismiss disability and old age in the way that she does? Clearly, she cannot see either as a source of strength, celebration or liberation in the way that race, class and gender can become through a process of struggle. Nondisabled feminists need to examine why not.

Feminist research places women's subjective reality (i.e., experience defined in the subject's own terms) at its core. However, when researchers (feminist or not) approach disabled people as a research subject, they have few tools with which to understand our subjective reality because our own definitions of the experience of disability are missing from the general culture.

If nondisabled people are to carry on doing research on disability – as they undoubtedly will – they need to consider how they can develop an understanding of our subjective reality. It is also important that they do the kind of research which turns the spotlight on the oppressors. Nondisabled people's behaviour towards disabled people is a social problem – it is a social problem because it is an expression of prejudice. Such expressions of prejudice take place within personal relationships as well as through social, economic and political institutions and, for example, a study of a caring relationship would therefore need to concern itself with prejudice (disablism), in the same way that studies of relationships between men and women concern themselves with sexism.

Disabled people's personal experience of prejudice must be made political – and space must be created for the 'absent subject' in the way that feminist research has done for nondisabled women. An example of research which needs to be done is that concerning the experience of abuse within institutions. Such research should seek to do three things:

- name the experience as abuse;
- give expression to the anger, pain and hurt resulting from such experiences;
- focus on the perpetrators of such abuse, examining how and why it comes about.

The disability movement has started to identify the different forms of institutional abuse that disabled people experience. One example is what has been called 'public stripping'. This is experienced by many disabled people in a hospital setting. For example, Anne, a woman with spina bifida, described her experience throughout her childhood when she was required by an orthopaedic consultant to be examined once a year. These examinations took place in a large room, with twenty or more doctors and physiotherapists looking on. After the hospital acquired videotaping equipment the examinations were videotaped. She described how, when she was twelve, she tried to keep on her bra which she had just started to wear. I quote from the article which described her experience: 'The doctor, in order to explain something about her back, took it off without saying anything to her, but with noticeable irritation. A nurse quickly apologised – not to Anne but to the doctor' (*Disability Rag*, Jan/Feb 1990). Anne knew that this kind of humiliation was inflicted on her because she was, as one doctor called her, 'significantly deformed and handicapped'.

BRENDA PRINCE/FORMAT

Disabled women protest against offensive stereotyping

The prejudice and the unequal power relationship which are an integral part of disabled people's experience of health services has led, in this type of situation, to both abuse and exploitation: abuse because privacy and personal autonomy have been violated, leading to long-lasting psychological consequences for many who have experienced this kind of public stripping; exploitation because, rather than being provided with a medical service (which is why people go to doctors and hospitals) people like Anne are actually providing a service to the medical profession.

All oppressed groups need allies and, by doing research which gives voice to our experience, feminist researchers can help to empower disabled women. However, nondisabled feminists must also ask themselves where are the disabled researchers? students? academics? If they are truly to be allies we need them to recognize and challenge both direct and indirect discrimination. Unfortunately, most nondisabled people don't even recognize the way that discrimination against disabled people operates within their workplace. Why do feminist academics put up with the way that most academic institutions fail to comply with the Disabled Persons (Employment) Act 1944 which requires them to employ a minimum of 3 per cent registered disabled people. Getting disabled people into the positions where we play a full role in carrying out research and disseminating it is as important for disabled people as the same process was and is for women. As Audre Lorde says, 'It is axiomatic that if we do not define ourselves for ourselves, we will be defined by others – and for their use and to our detriment' (quoted by Hill Collins, 1990: 26).

The relevance of feminism to disability research

My life as a feminist began with my recognition that women are excluded from the public sphere, ghettoized into the private world of the family, our standpoint excluded from cultural representations. When I became disabled I also realized that the public world does not take the individual, particular, physical needs of disabled people into account. Just as it assumes that children are reared, workers are serviced *somewhere else* – i.e., in the private world of the family – so people whose physical characteristics mean that they require help of some kind (whether this need is actually created by the physical environment or not) have no place in the public world.

As a feminist I recognized that men's standpoint is represented as universal and neutral. Simone de Beauvoir wrote, 'the relation of the two sexes is not quite like that of two electrical poles for man represents both the positive and the neutral . . . whereas woman represents only the negative, defined by limiting criteria, without reciprocity'. (1972, 15) Women have thus been excluded from a full share in the making of what becomes treated as our culture. When I became disabled I realized that, although disability is part of human experience, it does not appear within the different forms that culture takes – except in terms defined by the nondisabled (just as the cultural representation of women was/is defined by men). A lack of disability is treated as both the positive and the universal experience; while the experience of disability 'represents only the negative, defined by limiting criteria, without reciprocity'.

Rereading such classic feminist texts as a disabled woman, I felt that I had rediscovered the validity of such ideas all over again – it was almost like becoming a 'born again feminist'. My feelings of elation, however, were churned up with a powerful sense of exclusion for – although feminist ideas seem so relevant to disability – none of the works which I was reading acknowledged this.

The way in which a feminist perspective so obviously helps to make sense of the experience of disability illustrates the exciting potential for bringing a feminist analysis to more traditional disability research. There are two points which I want to make in this respect.

The role of research in personal liberation

For women like me, as Liz Stanley and Sue Wise write, feminism is a way of living our lives.

> It occurs as and when women, individually and together, hesitantly and rampantly, joyously and with deep sorrow, come to see our lives differently and to reject externally imposed frames of reference for understanding these lives, instead beginning the slow process of constructing our own ways of seeing them, understanding them, and living them. For us, the insistence on the deeply political nature of everyday life and on seeing political change as personal change, is quite simply, 'feminism' (Stanley and Wise, 1983: 192).

In a similar fashion, a disability-rights perspective – which identifies that it is the nondisabled world which disables and oppresses me – enables me to understand my experience, and to reject the oppressive ideologies which are applied to me as a disabled woman.

I look to disability research to validate this perspective (in the same way that feminist research has validated a feminist consciousness). Susan Griffin identified the way in which, during the 1970s, women

> asserted that our lives, as well as men's lives, were worthy of contemplation; that what we suffered in our lives was not always natural, but was instead the consequences of a political distribution of power. And finally, by these words, we said that the feelings we had of discomfort, dissatisfaction, grief, anger and rage were not madness, but sanity (Griffin, 1982: 6).

I look to disability research to confirm the relevance of these words to disabled people – our anger is not about having 'a chip on your shoulder', our grief is not 'a failure to come to terms with disability'. Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression which we experience.

Unfortunately very little disability research does anything other than confirm the oppressive images of disability.

The personal experience of disability

Disabled researchers such as Vic Finkelstein (Finkelstein, 1980) and Mike Oliver (Oliver, 1990) have been arguing for years against the medical model of disability and in so doing they have been making the personal political in the sense that they have insisted that what appears to be an individual experience of disability is in fact socially constructed. However, we also need to hang on to the other sense of making the personal political and that is owning, taking control of, the representation of the personal experience of disability – including the negative parts to the experience.

Unfortunately, in our attempts to challenge the medical and the 'personal tragedy' models of disability, we have sometimes tended to deny the personal experience of disability. (This is a tendency which Sally French discusses in the context of the experience of visual impairment, see French, forthcoming.) Disability *is* associated with illness, and with old age (two-thirds of disabled people are over the age of sixty), and with conditions which are inevitably painful. The Liberation Network of People with Disabilities, an organization which made an explicit attempt to incorporate the politics of the personal, recognized this in their policy statement. This statement included the point that, unlike other forms of oppression, being disabled is 'often an additional drain on the resources of the individual, i.e., it is not inherently distressing to be black, whilst it may be to suffer from painful arthritis' (*In From the Cold*, June 1981). To experience disability is to experience the frailty of the human body. If we deny this we will find that our personal experience of disability will remain an isolated one; we will experience our differences as something peculiar to us as individuals – and we will commonly feel a sense of personal blame and responsibility.

The experience of ageing, of being ill, of being in pain, of physical and intellectual limitations, are all part of the experience of living. Fear of all of these things, however, means that there is little cultural representation which creates an understanding of their subjective reality. The disability movement needs to take on the feminist principle of the personal is political and, in giving voice to such subjective experiences, assert the value of our lives (see Morris, 1991). Disability research can play a key role in this.

Into the mainstream

The experience of disability is part of the wider and fundamental issues of prejudice and economic inequality. Black people's experience of racism cannot be compartmentalized and studied separately from the underlying social structure; women's experience of sexism cannot be separated from the society in which it takes place; and neither can disabled people's experience of disabilism and inequality be divorced from the society in which we all live. That society is characterized by fundamental inequalities and by ideologies which divide people against each other – the experience of disability is an integral part of this.

Just as feminists ask how and why the public world assumes that responsibilities and tasks which take place within the private world will not impinge on the responsibilities and tasks of the workplace, so disability research must ask how and why the public world assumes a lack of disability and illness. It is such a focus which takes both women and disabled people out of a research ghetto for these are fundamental questions about the very nature of social and economic organization.

Disabled feminists (such as Nasa Begum – see Begum, 1990) are also demanding that nondisabled feminists put our concerns and our experiences firmly on to their own agendas. Just as Black feminists have insisted that feminist research has to address the experiences and interests of Black women so we are insisting that our experience is no longer treated as invisible. Why are we missing from feminist research on women and employment/unemployment, women and sexuality, women and housing, women and social policy, women and health? Unless such research covers our experience it can only be incomplete and inadequate, in terms of both its empirical and theoretical significance. Feminism is the poorer for its failure to integrate disability into the mainstream of its concerns and it has much to gain by redressing this omission.

Notes

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