

# Personal and Political: a feminist perspective on researching physical disability

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**ABSTRACT** *Feminist theory and methodology have much to offer in understanding how disability research has been experienced as alienated research by disabled people. However, feminist research has failed to apply its principles to disability and disabled women's subjective reality has found no place in mainstream feminist work. The paper identifies the challenges for feminism in addressing the interests and reality of disabled women, asserting that it is not helpful to focus on 'double disadvantage'. Disability research itself has much to learn from feminist methodology, in particular the principle of making the personal political. The role of non-disabled researchers as allies of disabled people is discussed, and the importance of research which turns the spotlight on the way in which non-disabled society oppresses disabled people. Finally, it is asserted that disability research and politics are of general relevance because the experience of disability is an integral part of a society characterised by fundamental inequalities and ideologies which divide people against each other.*

## Introduction

This paper is not really about gender and disability, except to point out that research which only includes disabled men is not ungendered research. Thus such research should be called a study of disabled men and not a study of disabled people; similarly research which only includes white disabled people should be called a study of white disabled people.

Neither am I interested in talking about whether disabled women experience a 'double disadvantage'—for reasons which will become clear. Instead, what I want to do is take the original aim of this series of seminars and the agenda laid down by Mike Oliver in his paper and look at what a feminist perspective might have to offer.

In the proposal for the series of seminars on researching disability which were funded by the Joseph Rowntree Foundation, the proposers identified that disability research has, in the main, been part of the problem rather than part of the solution from the point of view of disabled people. Such research, they said, has been severely criticised by disabled people because "it has been seen as a violation of

their experience, irrelevant to their needs and as failing to improve their material circumstances and quality of life". In his own seminar paper, Mike Oliver identified that disabled people experience disability research as alienation—in the sense of alienation from the product of research, from the research process, from other research subjects, and from one's self.

In that paper—and in other writings—he argued for the development of a new paradigm of research—emancipatory research. This must be based on: empowerment and reciprocity; changing the social relations of research production; changing the focus of attention away from disabled individuals and onto disablism society.

As a disabled researcher, seeking to incorporate a feminist and a disability rights perspective into my research, what can I contribute to these aims?

### **What Characterises a Feminist Perspective and What Makes it Relevant to Researching Physical Disability?**

My life as a feminist began with my recognition that women are excluded from the public sphere, ghettoised into the private world of the family, our standpoint excluded from cultural representations. When I became disabled I also realised that the public world does not take individual, particular, physical needs 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 recognised 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". Women have thus been excluded from a full share in the making of what becomes treated as our culture. When I became disabled I realised 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 non-disabled (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".

Patricia Hill Collins's statement (in her book *Black Feminist Thought*) has a doubly powerful meaning for me: "Groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others" (Hill Collins, 1990, p. 26). Making our standpoint known to both ourselves and to others is a central part of the feminist research agenda, as it must also be of a disability rights agenda.

### **What is Meant by the Term 'Feminist Research'?**

Women have previously experienced research as alienation. "Objectivity", as Liz

Stanley says, "is a set of intellectual practices for separating people from knowledge of their own subjectivity" (Stanley, 1991, p. 11)—or as Adrienne Rich once said, "Objectivity is a word men use to describe their own subjectivity".

Building on this recognition of research as alienated knowledge, feminist research is characterised by a method which, as Dorothy Smith says, "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, p. 107).

Does disability research do this for disabled people? Most of it clearly does not which is one reason why disabled people experience such research as alienation.

This quote from Dorothy Smith also reminds me of one of the reasons why I am uneasy about the use of medical and social models in disability research. Such models are problematic because they do not easily allow the space within the research for the absent subject. The use of models as an analytical tool comes from theory and research which treats us as objects. Is it possible to adapt such an analytical tool for the production of unalienated research?

As Dorothy Smith says in the context of feminist research on women, "The problem... is how to do a sociology that is for women and takes women as its subjects and its knowers when the methods of thinking, which we have learned as sociologists as the methods of producing recognisably sociological texts, reconstruct us as objects" (Smith, 1988, p. 109). This is the task for disability research also and, again, I am wary of the use of models for they come from a form of thinking which has treated disabled people as objects.

According to Liz Stanley, three things 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, p. 12).

### **How Have Feminist Research and Theory Failed to Apply Their Basic Principles to Disability?**

If we apply the above 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 non-disabled person holding certain cultural assumptions about disability; because the understanding and theorising have not been treated as taking place in the context of an unequal relationship between non-disabled 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'.

The feminist research on informal carers is a prime example of the production of alienated research from the point of view of disabled people—as Lois Keith's paper shows.

However, it is not just the way that feminists have treated disabled people within their research which is problematic, it is also how they have left disabled women out. This is clear if we look at the development of research over the last 20 years.

There were two stages to the development of feminist research. The first was that of '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 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 revolutionised. 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 about an entirely new way of looking at the world.

The most recent developments in feminist thought have focussed on a recognition of the experiences of different groups of women and the relationship between gender and other forms of oppression. Elizabeth Spelman, amongst others, has argued 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 theorising. 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', '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, p. 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 non-disabled 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, p. 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 anti-racism 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 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 recognise 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, p. 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, individualised; the definitions which society places on us centre on judgements of individual capacities and personalities. This lack of a voice, of the representation of our subjective reality, means that it is difficult for non-disabled feminists to incorporate our reality into their research, their theories, unless it is in terms of the way the non-disabled 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.

So where does this leave me as a disabled feminist? It means that I want to both

challenge feminism to incorporate the subjective reality of disabled women, but I also want disability research to incorporate feminist research methods.

## Two Challenges for Feminism

First, 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 individuals 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. My challenge to feminists is that they need to ask themselves whether these experiences of oppression are only of interest to disabled women.

The three examples illustrate different ways in which the oppression experienced by women and by disabled people intermesh. However, it is something of a red herring to spend much time analysing the relationship between sexism and disablism. What is more interesting to me is whether the experience of the women described above appears on the main agenda of non-disabled 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 non-disabled women.

Secondly, 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 emancipatory research (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.

If disability research is to be emancipatory 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 do not think that I,

or many other disabled women, want to read non-disabled researchers analysing how awful our lives are because we 'suffer from' two modes of oppression.

### **What Kind of Disability Research do I Want to See?**

I am interested in identifying the relevance of feminist theory and methodology for developing disability research which will empower disabled people. There are four main points which I would make in this respect.

(1) *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 & Wise, 1983, p. 192)

In a similar fashion, a disability rights perspective—which identifies that it is the non-disabled 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 took 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, p. 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.

(2) *The personal experience of disability.* Researchers such as Vic Finkelstein and Mike Oliver 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. Disability is associated with illness, and with old age (two-thirds of disabled people are over the age of 60), and with conditions which are inevitably painful. The Liberation Network of People with Disabilities, an organisation which made an explicit attempt to incorporate the politics of the personal, recognised 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.

When illness and physical difficulties—and old age—are so associated with personal inadequacies and are so painful to confront, it is also easy for us, in our attempts to assert control over our lives, to insist that we are young, fit, competent. The truth of the matter is that most disabled people are not young, are not fit, and have great difficulty in developing the competence to control our lives.

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. Disability research, if it is emancipatory research (in the way that Mike Oliver defines it), can play a key role in this.

(3) *Non-disabled researchers as allies.* All oppressed groups need allies. Non-disabled researchers have two roles as allies.

(a) Non-disabled academics and researchers should ask themselves where are the disabled researchers? students? academics? They should recognise and challenge both direct and indirect discrimination. Unfortunately, most non-disabled people don't even recognise the way that discrimination against disabled people operates within their workplace. 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 Lourde says, "It is axiomatic that if we do not define ourselves for ourselves, we will be defined by others—for their use and to our detriment" (quoted by Hill Collins, 1990, p. 26).

(b) Non-disabled people, if they make their living from being involved in the field of disability, should ask themselves whether/how they can do research which empowers disabled people.



Non-disabled 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? 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. Non-disabled people 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 non-disabled people are to carry on doing research on disability—as they undoubtedly will—what kind of research should they be doing?

(a) Turning the spotlight on the oppressors. Non-disabled 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 therefore needs to concern itself with prejudice, in the same way that studies of relationships between men and women concern themselves with sexism.

(b) Our personal experience of prejudice must be made political—and space must be created for the absent subject. This point is illustrated by an example of research which needs to be done—namely, research concerning the experience of abuse within institutions. Such research would have three aims:

- naming the experience as abuse,
- giving expression to the anger, pain and hurt resulting from such experiences, and
- focusing on the perpetrators of such abuse, examining how and why it comes about.

The disability movement has started to identify the different forms of 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 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 20 or more doctors and physiotherapists looking on. After the hospital acquired videotaping equipment the examinations were videotaped. She described how, when she was 12, 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".

The prejudice and the unequal power relationships 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.

(4) *Disability research and disability politics are of general relevance to all social groups.* This is not just because disability is found amongst all social groups but also because 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 compartmentalised 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 disablism and inequality be divorced from the society in which we all live.

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. Disability research must ask how and why the public world of work 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 organisations. Our society is characterised by fundamental inequalities and by ideologies which divide people against each other—the experience of disability is an integral part of this.

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