

Feminism, gender and disability

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My brief was to address the development of my own thinking on the relationship between feminism and disability since I first started writing on these issues; and to also talk about my current research interests and how they touch on feminism and disability.

When I became disabled, 15 years ago, I had already experienced a decade of feminism. Throughout my 20's I had been able to articulate my personal experiences of oppression through the politics of the women's movement. However, at the age of 33, when I was plummeted into a new experience of social exclusion, I soon realised that there had been no room within either feminist ideas or the women's movement for disabled women and that some of the views I had taken for granted were, in fact, highly questionable from my new standpoint - or at least from where I was now sitting.

I was extremely lucky that the disabled people's movement in Britain was gathering strength from the early 1980s and it gave me a political perspective with which to understand my personal experience. Nevertheless, the disabled people's movement also tended to treat disabled women's particular experiences as invisible; the concerns of the movement were framed to exclude issues of particular relevance to

disabled women.

So for the last 15 years I have, in a sense, been in a dialogue with both feminism and the disabled people's movement. It hasn't always been an easy conversation. Non-disabled feminists continue to treat disability as a side issue, an optional extra and in no way part of the so-called mainstream academic or political debates. The disabled people's movement - while many and sometimes the majority of its activists are women - is still informed by political and theoretical debates which strangely sideline women's experiences and issues.

Before I expand on any of this, however, I need to explain why I use the term disabled women rather than women with disabilities. To put it in a nutshell, the disabled people's movement in Britain doesn't use the term 'disability' to mean impairment but to refer to the disabling barriers of prejudice, discrimination and social exclusion.

The British Council of Disabled People recently adopted the following definitions:

'Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity. (Therefore, *disability*, like racism or sexism, is discrimination and social oppression).

Impairment is a characteristic, feature or attribute within an individual which is long term and may or may not be the result of disease or injury and may

1. affect that individual's appearance in a way which is not acceptable to society, and/or
2. affect the functioning of that individual's mind or body, either because of, or regardless of society, and/or
3. cause pain, fatigue, affect communication and/or reduce consciousness.

Disabled people are those people with *impairments* who are disabled by society.'

Like women, disabled people's politicisation has its roots in the assertion that 'the personal is political', that our personal experiences of being denied opportunities are not to be explained by our bodily limitations (our impairments) but by the disabling social, environmental and attitudinal barriers which are a daily part of our lives.

The social model of disability has given us the language to describe our experiences of discrimination and prejudice and has been as liberating for disabled people as feminism has been for women.

This is clearly illustrated by Liz Crow, in her contribution to *Encounters with Strangers*. She wrote:

Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me with an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.

For years now this social model of disability has enabled me to confront, survive and even surmount countless situations of exclusion and discrimination. It has been my mainstay, as it has been for the wider Disabled people's movement. It has enabled a vision of ourselves free from the constraints of disability and provided a direction for our commitment to social change. It has played a central role in promoting Disabled people's individual self-worth, collective identity and political organisation. I don't think it is an exaggeration to say that the social model has saved lives.

While the British disabled people's movement adopted the term 'disabled people' rather than 'people with disabilities' about 15 years ago, it has taken us a long time to consistently use the word 'disability' to mean oppression and to reclaim the word 'impairment' as a value-free word to describe characteristics of our bodies.

This development is reflected in my own writings: in *Pride against Prejudice*, I used the term disability to mean both oppression and impairment; in *Encounters with Strangers* I used it solely to mean oppression.

This clear separation of the terms disability and impairment is actually particularly useful for disabled women - it has enabled us to challenge the silencing of the experiences of impairment and illness. However, we still have a long way to go because it feels very dangerous to explore these experiences which have been used to say that our lives are not worth living. I want to come back to this issue at the end of this paper.

It must also be said that, while politicised disabled people in Britain may now feel comfortable with using the word impairment in a neutral way to describe something about our bodies, most people - disabled and nondisabled - are still uneasy with word because of its negative connotations. However, it is important for us to reclaim it in order to be able to separate out disability and impairment - this enables us to name our oppression.

I want to make four points about the general issue of 'gender and disability'.

1. A focus on 'gender and disability' should not be about examining the so-called 'double disadvantage' experienced by disabled women. Such a focus feels disempowering to disabled women. It is also an inevitable consequence of treating disabled women's concerns as a 'minority interest',

as an optional added-on extra to the concerns of both feminist analysis and that of the disabled people's movement.

The little analysis that there has been of disabled women's lives has tended to appear as a 'special' area of study, in (a very few) separate books and articles, and is often couched in terms of asking whether and how women with physical or sensory impairments and/or learning difficulties, encounter a 'double disadvantage' because of their experience of sexism and of disability. Usually these 'special' studies attempt to assess which is 'worse', which has the most serious effect on a woman's life chances.

I always feel uncomfortable reading about our lives and concerns when they are presented in these terms. I feel burdened by disadvantage and I feel a victim - such writings do not empower me.

As disabled women, we have to find a way of making our experiences visible, sharing them with each other and with non-disabled people, in a way which - while drawing attention to the difficulties in our lives - yet does not undermine our wish to assert our self-worth. In fact, feminist writing does not usually victimise the (nondisabled) women whose lives are the subject of research and analysis. Feminist analyses of women's oppression are themselves a way of asserting resistance, of struggling against oppression. Studies of women's experiences - although they are studies of the difficulties that women face in their lives - rarely present them as passive victims.

The way that we are seen as a minority interest, as a group experiencing 'double disadvantage' is very much related to the fact that disabled women do not have the opportunity to set the research agenda or to carry out the research, so our experiences are inevitably defined for us.

I have been lucky enough in recent years to be funded as a freelance

researcher and to use my involvement with the disabled people's movement to ensure that it is disabled people who set the questions I am addressing. I have also, as a feminist, attempted to use qualitative research to create a space for the absent voices¹ of disabled women.

This was particularly true when I was involved in a collective project with other spinal cord injured women which resulted in the publication of *Able Lives: women's experience of paralysis*, and when I carried out research on how people who need personal assistance in their daily lives experienced the different ways of receiving such assistance. Both projects illustrated that neither the feminist perspective nor that of the disabled people's movement adequately represented disabled women's experiences of receiving support in their daily lives.

For example, the disabled people's movement has campaigned for cash payments to enable people to purchase the assistance they need, so that they do not have to be dependent on either traditional social services or the assistance of family and friends. These campaigns have emphasised the importance of cash payments to enable people to have control over their lives so that they can enter the public world - whether it is getting a job or just being able to choose when you go out and where to. However, disabled women are - in addition and often more - concerned with having choice and control over the assistance they need to fulfill their caring role within the private world of the family.

¹ To paraphrase Dorothy Smith, who says that feminist research is characterised by a research method which, '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)

When we looked at women's experiences after spinal cord injury we found that:

As women, part of our return to 'normal' life is often a return to the pressures of looking after other people. Aids and adaptations which are supposedly about helping us to be [physically] independent are in fact often about enabling others to be dependent on us for the tasks which keep a house clean and a family fed. (Morris, 1989, p.52)

When I carried out research on the experiences of people who need assistance with the tasks of daily living, a quarter of my interviewees - all women - could also be described as 'care-givers' in that they were looking after other people within their family.

Feminist research about situations where people have to rely on their families for help with daily living tasks has, on the other hand, divided women into 'carers and their dependents' and has also made invisible the experiences of women who need such support. Instead, they have identified an 'equal opportunities' issue for non-disabled women whose economic position suffers because of the unpaid caring work they carry out within the family. Some non-disabled feminists have suggested that disabled and older women should therefore be consigned to residential care (for example, Dalley, 1988; Finch, 1990).

Neither the concept of independent living put forward by the disabled people's movement nor the feminist analysis of community care can be fully developed unless disabled women's experiences are put at the centre of the debate.

2. My second point concerns the way that a failure to include the interests of disabled women in research and analysis of social policy can result in a fundamental undermining of disabled women's human and civil rights.

This very clearly happened in the context of the research and policy analysis on community care. As I've already mentioned, feminist analysis in this field resulted in disabled and older women being excluded from the category of 'women' and classed as 'dependents' whose existence was a threat to nondisabled women's economic opportunities. Having silenced the voices of disabled and older women in the academic and media debates of the 1980s and early 1990s about 'carers and their dependents', this has continued in recent years with the identification of the children of disabled parents as 'young carers'.

This debate has particularly undermined disabled mothers as most of the situations where children are so identified are where women are parenting on their own.

Children of disabled parents have been described as 'little angels' who are forced to 'neglect their schoolwork and friends' in order to look after us. However, if we apply the social model of disability to the situation of disabled mothers we can see that there are a number of social factors which create the situation where children might have to provide some help to their parents.

Poverty is probably the most important one: impairment and illness often bring reduced earning power as well as higher daily living costs. Moreover, most of the research which identified households where children were providing some assistance to their parent were single parent households. The association of poverty with single parenthood therefore must also be a factor. Impairment and illness bring additional costs yet an increased risk of poverty also means that the resources are often not available to buy equipment or personal assistance. Disabled parents are often therefore forced to rely on others within their family for the help they need to go about their daily lives.

Another important barrier faced by disabled mothers is discriminatory professional attitudes. A few years ago the Maternity Alliance ran a conference for disabled parents and they shared their experiences of assumptions that they could not be fit parents (Shackle, 1993). The attitudes of health and social services professionals can actually deter disabled parents from asking for practical assistance because there is a fear that their children will be taken away.

Even when services are available they are often delivered in ways which are inappropriate and disempowering. Services can create a need for a child to help by restricting the amount and the type of assistance that will be provided. Disabling environments and inaccessible housing can also create a need for help.

A failure to understand the social model of disability lies at the heart of the dominant reaction to the situation where children are having to provide support to their disabled parent. Challenging the medical model of disability and the dominant concepts of independence and dependence can help us to promote disabled women's human and civil rights. This is illustrated by the following contrasting statements.

Disabling attitude

People who need help with the physical tasks of daily living are dependent.

If your child helps you put your shoes on, this involves a reversal of roles - you have become the child, and your child becomes your parent.

We need to recognise the role of 'young carers' so that we can support these children in their 'caring responsibilities, experiences and needs'.

We need to replace all the debate about 'young carers' with a clear understanding about what rights disabled people have to receive practical assistance in their home. Current British legislation, in the form of the Chronically Sick and Disabled Persons Act, does give us this entitlement. In many of the situations described in research and media stories about children of disabled parents, the parents had clear rights to practical assistance. Yet they were not getting these entitlements and unfortunately researchers and commentators have failed to highlight this.

We also need to link the issue to the wider campaign for human and civil rights. One local group in Britain is currently working to support 17 disabled

Disability rights perspective

Independence is not about doing everything for yourself but about having control over how help is provided.

The need for help with daily living tasks does not undermine your ability to love and care for your child.

Disabled parents should not have to rely on our children for help as we have statutory rights to 'practical assistance in the home' and to the adaptations and equipment we require.

mothers whose children have either been removed from them or who have been threatened with this. Most importantly, this needs to be identified as a feminist issue for it is to a considerable extent an issue for single parents - the majority of whom are women. The debate on 'young carers' feeds into the attack on single parents - in each case there is an implicit if not an explicit attack on women's ability to parent without the presence of a man in the household.

3. My third point concerns the way that the inter-relationship between gender and disability is a many faceted issue and is not in fact solely about women and girls. It could not be for both are social constructs which affect men as well as women. Gender as a social construct can be experienced in an oppressive way by men and boys as well as by women and girls and there is a danger that if we do not acknowledge the influence and interaction of both in men and women's lives any analysis or account of disabled people's lives can only be incomplete.

In *Pride against Prejudice* I looked at concepts of masculinity and femininity and how they were applied to disabled men and women. It's clear that masculinity as a social construct can be extremely oppressive for disabled men. Masculinity is about a celebration of strength, of bodies that perform, and of being a family's breadwinner. To be masculine is the opposite of being vulnerable and dependent. Some film critics have identified that film directors have used impairment (particularly that which involves using a wheelchair) to represent how awful dependency is for men. Disabled men are also frequently used as a cultural representation of evil. All this creates additional barriers for disabled men to contend with. There remains much scope for exposing the way disabled men and boys experience cultural stereotypes.

In my current research area - the experiences of disabled children and young people - it is also clear that there is complex relationship between gender and disability in terms of their impact on disabled children's

experiences and life chances.

For example, in Britain a key way in which disabled children are still segregated and excluded from society is the practice of sending them away to residential schools. This often masquerades as a response to their educational needs but is in fact often a response to (a) the failure of so-called mainstream schools to cater for all their local population and (b) parents's difficulties in coping with looking after children with significant support needs and/or difficult behaviour in the context of inadequate and/or inappropriate support.

Most disabled children sent away to boarding school are boys. My research looked at three local authority areas and found that in each area more than three-quarters of the children sent to boarding school were boys². Yet there has generally been a failure to recognise this.

This may partly be because disabled children, like disabled people, are not recognised as being differentiated according to sex or gender. We need further research on why disabled boys are more likely to spend the majority of their childhood away from their families, on what are the implications of this for services, and what are the implications for disabled boys and girls themselves.

² There are slightly more disabled boys than girls in the population but the imbalance is nowhere near as significant as amongst those who go to boarding school. The figures for disabled children at boarding school concern those with physical and/or sensory impairments and/or learning difficulties, and do not include those whose primary educational need is emotional and behavioural difficulties. For more details see Morris (1998).

4. My final point concerns an issue I mentioned earlier - the way that disabled feminists have challenged the disabled people's movement to address the experience of impairment. Unless we do this we cannot develop a credible politics in the debates on prenatal testing, abortion and euthanasia.

If we clearly separate out disability and impairment, then we can campaign against the disabling barriers and attitudes which so influence our lives and the opportunities which we have. However, in focussing on the external barriers we have tended to push to one side the experience of our bodies. Indeed, we have in some ways been forced to do this because of the way that our bodies have been considered as abnormal, as pitiful, as the cause of our lives not being worth living. Sensory impairment, physical impairment, intellectual impairments are seen as things to be avoided at all costs. In the face of this prejudice we have asserted that anatomy is not destiny - in the same way that feminists assert that anatomy is not destiny - and that it is instead the disabling barriers 'out there' which determine the quality of our lives.

However, in doing this we have sometimes colluded with the idea that the 'typical' disabled person is a young man in a wheelchair who is fit, never ill, and whose only needs concern a physically accessible environment. In fact, the majority of disabled people are women, are over the age of 60, have a chronic or progressive condition such as arthritis or MS, feel unwell a lot of the time and if they use a wheelchair they only do so occasionally. We also do a great disservice to people with learning difficulties and to people with mental health difficulties.

Yet when I have tried to raise the importance of addressing the actual experiences of our bodies, I have been accused of 'not dealing with the real world' and of feeding into nondisabled people's pity of us. Indeed, I worry myself that if we *do* start talking about the reality of living with impairment

and illness, nondisabled people will turn round and say, there you are then, we always knew that your lives weren't worth living.

This means, however, that we forced into situations of denying the experience of our bodies, of trying to conform to the outside world's view of what it is to be a proper person. This kind of pressure is described in a piece of writing in *Mustn't Grumble*, a collection edited by Lois Keith. This piece describes the way one disabled woman feels that, when out in public, she must counter the negative way that people react to what she looks like and how her body behaves - in this particular case a man coming towards her down the street.

'Seeing the averted gaze of pity, she found herself preparing for the moment when they would pass one another on the narrow path. She could not help herself from wanting people, even complete strangers like this man, to notice that although she might be dragging herself along like a wounded animal, her eyes were bright, she had a ready smile and her voice, if he should have reason to hear it, was up and out; confident.'

It was an American older woman who wrote: 'If I feel shame in my lack of strength, I will have let someone else in my head for the rest of my life.'
(Macdonald, 1983, p.32)

Living in a sexist and a heterosexist society as we do, all of us, nondisabled and disabled women, find that our behaviour and appearance is policed by men. Sexist and heterosexist values tell us what kind of appearance we should aim for, what kind of behaviour is acceptable. Society's reaction to impairment, to bodies which are very different from the norm, means that disabled women are either attractive in spite of their impairment or unattractive because of their impairment. There is no room for what impairment and difference mean to us.

As Liz Crow writes in *Encounters with Strangers*, we need to put back the experience of impairment into our politics. We need to write about, research and analyse the personal experience of our bodies and our minds for if we don't impose our own definitions and perspectives then the non-disabled world will continue to do it for us in ways which alienate and disempower us. Some people have reacted to this position by saying that there is nothing political to be said about impairment - impairment belongs to the personal world where everyone is different and there are such variations in individual experiences that there are few generalisations to be made. This is a bit like saying that women's experiences of, for example childbirth, are merely personal and individual; that there are no political demands to be made based on the personal experiences of our unequal relationship with doctors, the lack of recognition of the role and expertise of midwives, the denial of autonomy in how we give birth, the professional highjacking of the recognition of pain and the administration of pain control, and so on.

The problem is that if we don't express the experience of our bodies, others will do it for us. If we don't confront what we need as a result of illness, pain, chronic conditions which inhibit our lives, then health services and support services will continue to be run in ways which disempower us. If we don't engage in the debates about old age then when we get there we will find that the battles we thought we had won as younger disabled people are of no use to us whatsoever.

Adrienne Rich said it all in her poem:

'The problem, unstated till now, is how
to live in a damaged body
in a world where pain is meant to be gagged
uncured, un-grieved-over. The problem is
to connect, without hysteria, the pain
of anyone's body with the pain of the body's world.'

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