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Disabled Sexuality: Toward Rights and Recognition

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Looking back at the development of disability sexuality studies, there is a need for a social model of disabled sexuality. However, this should be sensitive to difference, including the impact of impairment. Disability sexuality studies necessarily challenge notions of sexual normality. There is a danger in overstating the importance of sex, as opposed to friendship and intimacy. Honneth's work on relations of recognition may offer a way to conceptualise sexuality issues within the disability rights agenda.

KEY WORDS: public/private distinction; social model; normality; civil rights; recognition.

INTRODUCTION: SEXUALITY WITHIN DISABILITY STUDIES

When Dominic Davies, Kath Gillespie-Sells and I researched and wrote *The Sexual Politics of Disability* (1) between 1994 and 1996, it was striking that issues of sexuality and relationships had a low profile in the British disability movement, and in the developing field of disability studies. It had been suggested, by disabled feminists such as Jenny Morris, that disability studies was reproducing the same old academic problem, of talking about disabled people, when in reality it was relevant only to disabled men (2). However, we felt that something else was going on. The divide between the public and the private, which feminists had also identified, was the key factor explaining the neglect of issues of sex and identity within disability politics.

That is, the public lives of disabled men and women were up for analysis, for discussion, and for campaigning. The demand for access to public space, for an end to discrimination in education, employment and other areas of life, and for the development of collective responses to oppression was all about making

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personal troubles into public issues. But the private lives of disabled women and men were not seen as being equally worthy of concern, in most radical circles. It has to be remembered that the social model emerged twenty years ago, when the notion of the personal as political was only just emerging from the women's movement, and in Britain, where sexual repression and the double standard is the norm.

Partly, this is undoubtedly about prioritisation. Ending poverty and social exclusion comes higher up the list of needs, than campaigning for a good fuck, and for access to clubs and pubs. I think the neglect may also have to do with the ways in which the disability movement in Britain consciously tapped into the tradition of labour movement organising, and adopted the paradigms of trades unionism and socialism, rather than the paradigms of consciousness raising and feminism. Male, instrumental, public, rational and material concerns were seen as more pressing than domestic issues. Looking at some of the macho politics of disabled direct action, and at some of the confrontationalism and anger and bitterness displayed by activists also gives some clues as to why relationships and intimacy and child-rearing may not have been on the agenda.

Thirdly, I think that sexuality, for disabled people, has been an area of distress, and exclusion, and self-doubt for so long, that it was sometimes easier not to consider it, than to engage with everything from which so many were excluded. Talking about sex and love relates to acceptance on a very basic level—both acceptance of oneself, and acceptance by significant others—and forces people to confront things which are very threatening, given the abusive and isolated lives of many disabled people. As Anne Finger suggests "Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction" (3).

FROM THE MEDICAL TO THE SOCIAL MODEL OF DISABLED SEXUALITY

Steven Seidman has argued as follows: "Sexuality is perhaps the last human dimension that many of us refuse to grant is socially created, historically variable, and therefore deeply political" (4). But I think all those of us who gathered at the San Francisco conference would refute this suggestion, and claim that even more than sexuality, disability is seen as natural, and individual and medical, and inexorable. The major contribution of British disability studies has been to demonstrate that disability can only be understood as the outcome of social and economic and structural relations, not as the result of the deficits of body or brain (5). Rather than taking disability for granted, and campaigning for a better deal for these unfortunate people with disabilities, the British approach has been to deconstruct and challenge the ways in which society disables people and creates the problem of disability.

While the social model has been used to highlight the failures of contemporary social organisation, the badly designed transport, the prejudiced attitudes, and the discriminatory employers which disable people, it needs also to be used to show that the problem of disability and sexuality is not an inevitable outcome of our bodily differences. It is not because we cannot walk, or we cannot see, or because we lack feeling in this or that part of the body that disabled people have sexual problems. The solution is not more prosthetics, or more Viagra, or any other physical or clinical intervention. As we argued in our book, the problem of disabled sexuality is not how to do it, but who to do it with. The barriers to the sexual expression of disabled people are primarily to do with the society in which we live, not the bodies with which we are endowed.

Let me recap some of these problems, as recorded by the people we spoke to for our research. To be sexually active, it helps to have had sex education at school. As Leonore Tiefer writes,

> Imagine how you would feel if playing gin rummy, and playing it well, was considered a major component of happiness and a major sign of maturity, but no one told you how to play, you never saw anybody else play, and everything you ever read implied that normal and healthy people just somehow 'know' how to play and really enjoy playing the very first time they try! (6)

For many disabled people, in segregated institutions, sex was never on the agenda, and wasn't seen as being part of the story.

It also helps to have someone to have sex with. Most people meet potential partners at college, at work, or in social spaces. Unfortunately, disabled people often don't get to go to college, or to work, or achieve access to public spaces, because of physical and social barriers. Being sexual costs money. You need to buy clothes, to feel good about, and go places to feel good in. If you are poor, as 50% of disabled Americans are, then it is correspondingly harder to be sexual.

More than money, being sexual demands self-esteem. It demands confidence, and the ability to communicate. We all know that it isn't just the size of your dick, or the shape of your body that counts when it comes to attracting potential partners, nor even the size of your wallet; it's what's between the ears. If you feel good about yourself, and project that self-assurance, it is far more likely, whatever you look like, that others will take you seriously and see you as a potential partner. Yet disabled people, systematically devalued and excluded by modern western societies, are often not in the right place to begin that task of self-love and self-worth. Ironically, the disability movement, which has concentrated so hard on instrumental goals such as civil rights and which has neglected sex and identity, may have made far more of an impact in the lives of its participants through the increased sense of pride and self-esteem which the participation and the symbolic challenge often inculcates.

Before moving on from this discussion of social models of sexuality, I think it's important to record that my current position on the social model has moved from the time we wrote the book. My feeling is that we cannot ignore the role of impairment and the body in our lives. A social constructionist approach that loses contact with the physical does us no favours. I think we have to have a position that recognises difference, and limitation, and the very real problems which disabled people may have with their bodies and their lack of function.

This suggests also that differences between disabled people between disabled people are very important. These include issues to do with class, gender, race and sexuality. But it also includes the different relationships people have to their impairment. There will be differences due to the age of onset, between people with congenital impairments, people with acquired impairments, and people who become impaired due to ageing. There will also be differences to do with the impact or nature of impairment: we often think mainly of motor impairments, but clearly other impairment groups—such as people with sensory impairments and people with learning difficulties—will all have different issues around sexuality. We do not need to suggest that impairment itself is determining—the social response and cultural meaning will usually be the critical element—but I believe it is important not to lose sight of the differences between different groups and individuals in the disabled community.

In the second half of this paper, I want to go on to raise two questions, and offer one way forward. But before I do that, I want to suggest one warning about this move to the political disability agenda, and the social model of disabled sexuality. We do not want to reject the idea that disabled people are victims of their malfunctioning bodies, only to adopt the idea that disabled people are victims of an oppressive society. That is to say, any account of disability has to show the ways in which people resist disabling barriers. It has to show that people can and do overcome discrimination and prejudice. There is a great temptation, within disability politics, to play the game of who is most oppressed, and to speak from the victim position, but there are costs to that game, and I believe that disabled people have to reject that strategy, and to be proud and strong and to celebrate our resistance and solidarity and achievement.

DO WE WANT TO BE NORMAL?

In exploring disabled sexuality, we are faced by similar questions to the lesbian and gay activists and scholars who have explored gay and queer sexual politics. Are we trying to win access for disabled people to the mainstream of sexuality, or are we trying to challenge the ways in which sex and sexuality are conceived and expressed and limited in modern societies?

One strategy would build on Wolfensburger's notion of normalisation, and campaign for disabled people to have access to the same sexual expression as everyone else. Many disabled men and women follow this approach. They reinforce taken for granted assumptions about gender and sexuality, but struggle for acceptance on those terms. They might work out, and take part in paraplegic sports, and get drunk, and beat up their partners, and deny that there is any reason why they can't be just as macho—or as feminine—as non-disabled people. They might wear prosthetics or use Viagra or talk about their 'supermanhood,' in terms that validate the prevailing categories and myths of masculinity and femininity and consumer culture.

But there is an alternative, which many disabled people are reaching out for. Rather than struggling to conform and to fit in to stereotypes which developed on the basis of exclusivity and the body beautiful, and narrow, limited notions of how to behave and how to look, disabled people can challenge the obsession with fitness and youth and the body, and demonstrate that sexual activity and sexual attraction can be whatever you want it to be. Many disabled people in our survey (1) felt that conventional notions of male and female and straight and gay did not apply to them. As one man said,

> One of the interesting things, I feel, is that with the exception of gays, males don't get hassled, whereas you suffer a form of sexual oppression as a disabled man. I very much see myself as a disabled man, not a heterosexual man. (Eddie)

In the way that they acted, and in the way they made love, and in the way they dressed, they felt liberated to play with roles and images and ways of being.

We can perhaps challenge a whole lot of ideas that predominate in the sexual realm, and enable others—not just disabled people—to reassess what is important and what is possible. Why should men be dominant? Why should sex revolve around penetration? Why should sex only involve two people? Why can't disabled people be assisted to have sex by third parties? What is normal sex? We know that sex doesn't have to be connected to love, and that neither needs to be connected to reproduction, so there is nothing to limit us except the need for respect for each other, and to look after each other's safety. Just as HIV and the invention of safer sex challenged gay men to use their imagination and find new and different ways of having sex, so the limitations of impairment should create different options, not close down possibilities. As one disabled woman told us,

> I see my limitations only as parameters: my normality, my sexuality, to be pushed right to the edge. If you are a sexually active disabled person, and comfortable with the sexual side of your life, it is remarkable how dull and unimaginative non-disabled people's sex lives can appear. (Penny)

DO WE WANT MORE SEX?

This seems like a stupid question. We live in a culture in which sex is omnipresent. If in the nineteenth century people couldn't mention sex, but were everywhere upfront about death, now we cannot mention death, especially in California, but sex is de rigeur. In modern life, bodily pleasures are central to consumer culture, and consumption is the key word. As individuals, we demand the right to be sexual and to choose whatever form of sexual expression or fulfilment we can find. We live in the 'market of free emotions.' In late modernity, potential sexuality is omnipresent. We know about the fascination with gay male culture, which is particularly a fascination about the availability of sex. The modern media, the modern fairy tale, is about the possibility of sexual adventure in every public place. We live in an age where desire itself is the thing to be desired.

Our book, and the San Francisco conference, are part of that. We want to sexualise disabled people. We want to challenge exclusion. We demand the right to be hot and sexy. Yet do we really want more sex? Perhaps because we haven't had access to it, we've been in danger of overstating it. I will make three suggestions:

1. Most people are not having good sex, most of the time. Germaine Greer has written critically about the notion that everyone is having great sex. There's a lot of media hype going on about sex in the culture: we might call it the Cosmo conspiracy. Perhaps it is more accurate to suggest that we can all hope for a few great sex moments from time to time, but otherwise the average sex life is pretty mundane.
2. Sex is not that important. It's not vital to happiness. In England, everyone laughed when Boy George, the singer from Culture Club said that he'd rather have a cup of tea than sex. But maybe his heresy isn't so far from the point. Tiefer reminds us of a historic study in *New England Journal of Medicine*. A survey of 100 self defined 'happy' couples found that there was some sort of arousal or orgasm dysfunction in the majority of cases but that the couples considered themselves happy both sexually and non-sexually nonetheless (7). Surveys in Britain, apparently, have found that more women preferred gardening to sex.
3. Most people are not looking for sex itself, they are searching out intimacy, warmth, validation, connection. That is, relationships rather than sex are what counts. This sensitizes us to the importance of friendships. It might suggest that researchers explore the issue of physical touch, and the lack of intimacy in many disabled people's lives.

I want to suggest that our cultural obsession with sex may be unhelpful. It creates a desire which can never be fulfilled. As Zygmunt Bauman writes "The ultimate sexual experience remains forever a task ahead and no actual sexual experience is truly satisfying" (8). And if this is true for people in general, maybe it is particularly true for disabled people. Do we really want to raise expectations, and pretend that it's all easy and available and straightforward and fulfilling? To see sex as the whole story is to buy the message of the soap opera melodrama. Perhaps we shouldn't forget to value celibacy, and friendship, and the other parts of life.

CONCLUSION

So, having asked some questions, let me move toward a conclusion. And here I want to go back to what I said at the outset about the public private distinction. I think one of the tasks for us here, and in our work, is to put private desires and personal relationships on the agenda of the disability movement, to make them an arena for change. The British disabled feminist Liz Crow wrote:

> I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for—employment, education, housing, transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for.[. . .] It's not that one area can ever be achieved alone—they're all interwoven, but you can't get closer to the essence of self or more 'people-living-alongside-people' than sexuality, can you? (9)

British gay theorist Jeffrey Weeks has been developing the concept of sexual citizenship, which might help us here (10). He talks about this in terms of finding a home for difference, and about making a claim for belonging. There are three dimensions to this process. First, is a demand for control: we demand control over our bodies, over our feelings, and over our relationships. Second, is a demand for access: we demand access to representations, relationships, and public spaces. Third, is a demand for choice: we demand choices about identities, our lifestyles, our gender experiences. And while this threefold approach was developed from the lesbian and gay agenda, I think it speaks to us here today in the disability community as well.

And finally, I think that reconciling the public and the private also means connecting the individual experience of the body, to the collective experience of social structures. Here, I find the work of Axel Honneth particularly suggestive (11). In his book, *The Struggle for Recognition: the moral grammar of social conflicts*, Honneth draws together the work of Mead and Hegel. He develops a normative ideal of a society in which patterns of recognition would allow individuals to acquire the self-confidence, self-respect and self-esteem necessary for the full development of their identity. His model connects three levels: the primary relationships of love and friendship; the legal relations of rights; and the solidarity which emerges from a community of value. For him, having legal rights is about recognition, and is a means to self-respect. A state of societal solidarity exists when every member of a society is in a position to esteem himself or herself.

Therefore, our work around disabled sexuality should not be narrowly defined as a matter of sexual desire and physical entwining. It should form part of a revisioning of the disability movement's mission which encompasses identity and solidarity and rights and respect in every area of the lives of disabled people, and which builds an inclusive community of disabled and non-disabled individuals. It should also form part of revisioning the role of sex in the twenty-first century. Let me conclude with the words of the disabled American Cole Porter: "Let's do it. Let's fall in love."

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