

Chapter Seven (in *The Sexual Politics of Disability: Untold Desires*, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 182-205)

Seven

Making a change

Introduction

In this final chapter, we will explore the changes which are needed in order to achieve the sexual rights of disabled people. Some of these changes are already well under way: others are only just being fought for. We argue that there are three sorts of change. First, and most important, there is the change that needs to take place in society, in order to remove the barriers against the participation of disabled people. These barriers are not just physical, they involve government policies, professional ways of working, media representations, and public attitudes. Over and over again in this book we have highlighted the lack of access, discrimination, poverty, prejudice, and isolation. Social action on a massive scale is necessary if the situation in which the majority of disabled people live is to change, as it must.

Second, there is the change which needs to take place in our communities: in the disability movement, in the lesbian and gay movement, in the women's movement. There are too many inconsistencies and contradictions. It needs to be reasserted that unless there is liberation for all there is liberation for no one. Within identity group politics, it has always to be remembered that there are minorities within minorities, that there are multiple oppressions, and that being progressive about one issue does not automatically mean being progressive about other issues.

Third, there is the change which needs to take place within ourselves as disabled people. The only true empowerment is self-empowerment. It has not been our intention in this book to portray disabled people as victims. We believe that only disabled people can achieve the liberation of disabled people, and for that they need to develop a sense of their own

strength and resources. Disabled people's lack of self-esteem is a product of the socialization, the experience of discrimination and prejudice, the marginalization, which characterizes the disability experience. The mobilization of disabled people is about challenging that oppression, and it is about developing a positive self-consciousness. The external process and the internal process are related to each other and reinforce each other (Shakespeare, 1993). There is a tendency within disability studies literature only to explore the barriers and structures which disable, which can sometimes detract from focusing on the individual strengths and potentials of disabled people, as social actors, to resist and create space for change.

Cure?

Because disability has traditionally been seen as a medical problem, there is a widespread perception that the answer to the disability issue is the development of physical cures. Non-disabled people view disability as the ultimate tragedy, a disaster which makes life not worth living, and so they feel cure must be the only answer. The non-representative charities which dominate the disability field also follow this approach. In many cases, they are no more than organized cheer-leaders for the medical profession, raising money for research into potential clinical interventions. Parents, too, often feel that the answer to their child's problem is to invest time, money and energy into a desperate search for a medical solution. In all these ways, disability is individualized, the person with impairment is seen as a problem, and the impaired body is seen as broken, ugly, and useless.

However, despite society's negativity about disability, the majority of our interviewees would not choose to change their situation and become non-disabled. Part of the explanation for this rejection of a cure may lie in the fact that many of our interviewees are politicized disabled people. Disabled people want social change, not bodily cure. This account by Patrick shows both the pressure to be cured, and also disabled people's lack of interest in cure:

‘Even when I was a baby I was taken to Lourdes by my mother to be dipped in the water and prayed for a cure. I have one memory of being

hauled off to the church one Sunday, a priest coming round, with a special aisle of nineteen people and I didn't particularly want to take part in this, but my mother dragged me in and made me put my hands out to be blessed.

'I don't really think I want a cure now, I honestly think if I was cured now instantaneously, [...] that would not cure everything at all, that would only cure the physical issue. I would have to do a lot of adjustment, starting out with learning how to drive and I think even if I did have full sight, how to make use of it, how to actually walk around and see, as in the process of looking and working out things while you do, you look at things and work out what's happening. How to learn, how to see all this extra light that's coming into my eyes. I would have to spend a lot of time readjusting to this so-called full vision, if I was cured. It might mean changes to the way in which I deal with people. I'd be able to see their faces, learn how to work out what they actually ... when you say something being able to see how their face would react. So there would be a lot of learning involved, and so I don't think by just curing me suddenly one morning, would suddenly make my life better ... it would certainly make a change. Finally, I don't really think about wanting to have a cure all the time, I don't personally go off to religious shrines. I do take an interest, when an electronic eye was being developed in America, yes of course I did listen to it, but I think really I'd rather spend my time putting my energy making the world adapt accept disabled people, rather than working on cures.'

The assumption that disabled people would readily jump at a cure is a myth central to the Christian tradition, compounded by the likes of American religious evangelical Morris Cerullo, who equates disability with sin. He believes his role is to remove the sin of impairment. However, disabled people are clearly stating that the changes they wish to see are the removal of barriers to leading full and active lives, not changes in their physical difference. Phillipe explains:

'I just can't imagine becoming hearing, I'd need a psychiatrist, I'd need a speech therapist, I'd need some new friends, I'd lose all my old friends, I'd lose my job. I wouldn't be here lecturing. It really hits hearing people that a deaf person doesn't want to become hearing. I am what I am!'

We would not wish to imply that all impairments are the same, or that all disabled people are the same. Neither are all therapeutic interventions the same. Some procedures have a clear benefit for disabled people: they minimize the discomfort or pain of impairment. Other procedures seem to have a more cosmetic function. They are about normalization or fitting disabled people into a society which is unwilling to change. Examples of this second category include limb-lengthening for people with restricted growth; cochlear implants for deaf people; cosmetic surgery for people with Down Syndrome.

It is important to point out that disability (social restriction) often makes impairment (physical restriction) more problematic: Zorah's response shows how disabled people often want a cure to make life easier in a world which does not accept difference.

'At one time I would have said that I was proud to be a cripple but at the moment I am totally fed up of the ways access is denied me and places I want to go, and fed up of being tired all the time and in pain'.

Those who are keen for a cure to their impairment may nevertheless not want to leave the disabled community. Asked if she would take a cure, one woman said:

'This is hard. ..sometimes. ..when I can't reach or encounter a non-accessible place I wish I could just walk, but it would be very strange to be suddenly cured and not part of the disabled group of people I'm getting to know. I'd be losing something and gaining something, but I couldn't choose now.'

We have shown how being a disabled person means being marginalized and isolated. No wonder that people like Veronica would welcome an alternative:

'Yes, I would opt for a cure because I find being disabled so difficult and frustrating and being disabled makes me feel extremely angry. I feel it is unfair. '

To conclude this discussion, it is important to challenge the notion that all disabled people desire to be cured. However, it would be equally wrong to ignore the issue of impairment, and the desire of many disabled people to avoid the pain and discomfort which it brings. But we need to reiterate that the main problems of disability are social, not physical.

Political change

Since the early 1970s, more and more disabled people have been involved in a dialogue about their needs, hopes, and desires. They have formed organizations run and controlled by themselves and have demanded civil rights. The disability movement has achieved a great deal by pushing the boundaries of acceptance and asserting the notion of equal rights. 'Rights Not Charity' was the major slogan of the late 1980s. It was a reminder of our history of patronage and handouts. Of our status as receivers, not providers and of the notion that we should be grateful for whatever meagre pickings we received. Disabled people swelled behind the 'rights' banner. Increasing frustration at the apparent inertia of politicians and failure of service providers to make the required changes was matched by growing determination of the movement of the early 1990s, which demanded rights across the board.

Although the discrimination experienced in the arenas of education, employment, and transport had been of major concern for many years, the demand for full comprehensive anti-discrimination grew in momentum and the call for 'Rights Now!', i.e. rights to full and equal participation, became the major battle cry. The 1995 Disability Discrimination Act was not the comprehensive legislation demanded: it was a Conservative government compromise. Although the unrepresentative disability organizations have fallen in with the government agenda, the grass-roots disability movement continues to campaign full civil rights.

Two major strategies of the disability movement have been instrumental in asserting the political demands, challenging perceptions of disabled people, and building the disability community around a notion of pride. First, disabled people have emulated other civil rights movements and used non-violent direct action as a tactic for change. By bringing city

centres to a standstill and by blockading charity telethons, disabled people have served notice that they will not tolerate exclusion and patronage. These actions have not only forced change and achieved high-profile media coverage, they have also challenged the image of disabled people as passive victims, and contributed to the new self-confidence and assertiveness of disabled people.

Second, the disability arts movement has developed new cultural forms to highlight the disabling barriers in society, and to celebrate disabled people's strength and survival. Drama, cabaret, writing and, visual arts have been harnessed to challenge negative images, and build a sense of unity. Disability arts events would appear to provide not only a means of expression of views about the experience of disabled people in a disabling society but also an important opportunity to meet potential partners. As Stuart states:

'As the movement grows in numbers, more and more disabled people are coming together and meeting each other at disability arts events. They are forming relationships and actually saying "Sod society, we will actually get together, we know it will be a hassle but we can do it".'

Concerted pressure has also forced the major television companies to support disabled people's self-expression by training, resourcing, and commissioning disabled film-makers. However, there is still some way to go before we have disabled newsreaders or disabled people in soaps who are there without their impairment being an issue. As Eddie states:

'We need more people in the media, people with power who are disabled people because you would see a better conception of us.'

Julie takes it one step further:

'It's high time there was a glossy video with passionate images of disabled people being sexual, discussing sex and sexuality and exploring safe sex, sex aids, HIV issues. The Kama Sutra for bonking crips ...etc.!!'

Political change is happening at a local level too, through Centres for Integrated Living, and other disabled-controlled coalitions and service

providers. This movement offers the potential to overcome the barriers to independent living, and the reliance on partners and other family members, that often are the major problems for ordinary disabled people.

Another important contribution to an understanding of disabled people's position in society has been the development of awareness- raising courses, designed and run by disabled people themselves. These courses have presented non-disabled people with an alternative view to the traditional ideas of disabled people as passive recipients of services. Being presented with course tutors who are trained trainers and disabled people has in itself been a major challenge to the myth of disabled people as incompetent. Phillipe, a deaf trainer, describes a common reaction to him as a trainer.

'Often I talk about deaf awareness training, I go around doing that, and they [hearing people] are quite shocked that a deaf person can be a presenter, to teach sign language. A deaf person can't do that, they expect a hearing person.'

Until quite recently disability equality training has primarily addressed itself to access and employment or housing. However, with the growing numbers of disabled people living independent lives in the community, more complex issues of relationships, sexual practice, domestic violence and parenting have been on the agenda. Service providers have been seeking advice from disabled trainers or consultants about the development of sexuality policies and good practice guidelines on sexuality. Kit, a trainer herself, had recently run some workshops where the issue of parenting was a major issue. Passing on genetic impairment or, for parents with acquired impairments, the way impairment impacted on their relationship with their children were issues that needed further work. She states

'I'm coming to realize that the disability equality issue has been quite narrow, we address employment as far as we can, but for example, domestic violence is something a huge percentage of disabled women could talk about.'

Thus disabled people are changing the perceptions of non-disabled people by means of training courses that describe the reality of their lives and challenge accepted 'norms' about disability. Disabled trainers are also providing courses on empowerment for other disabled people, working on role models, and providing a challenge to non-disabled behaviour modification.

Inevitably, a brief section on the contemporary political changes cannot do justice to the richness and variety of disabled people's initiatives. However, there are now many publications which explore these developments, and to which we would refer the reader (Morris, 1991; Swain et al., 1993; Campbell and Oliver, 1996).

Changing the disability movement

Since the formation of the Union of the Physically Impaired Against Segregation (UPIAS) and the Liberation Network of People with Disabilities in the 1970s, disabled people nationwide have become increasingly involved in the struggle for change. Many have felt fed by the solidarity and have readily become involved within their local communities and at national events. However, it would appear that not all disabled people feel welcome.

It would be true to say that the disabled people's movement is a microcosm of society and reflects the power-base and status quo that exists in Britain today. Although we have had women (albeit predominantly white, middle-class, heterosexual women) in positions of power within the movement, it is predominantly, white, middle-class, heterosexual men who represent the movement as a whole. Understandably the focus of the movement's attention has been the discrimination and disadvantage experienced by disabled people on grounds of impairment. However, there are black and minority ethnic and lesbian and gay disabled people who feel their particular concerns have been overlooked, in the struggle to achieve rights for the majority. Julie believes:

'The disability movement should be changing attitudes and addressing the politics of exclusion around lesbians and gays in particular. [...] Let's

have a national conference to air our joys and pains, exchanging ideas and so on. We're too sexy for this ignorance.'

This is not an unusual phenomenon: many movements in their desire to achieve positive change do so whilst ignoring or not recognizing the importance of including minorities within that community.

Black disabled people and lesbian and gay disabled people have formed their own groups to provide support and to apply pressure for inclusion of their issues by the majority movement. Black and Asian disabled people have challenged the disabled people's movement to examine its own racism, to look at policies and practices and examine why there are so few black disabled people involved. As Mildrette Hill has written (Hill, 1994: 79):

Black Disabled people argue that the time is well past due for organisations to be set up to ensure that they have a full and equal say in the policies and practices which affect their lives. [...] They maintain that as long as Black Disabled people are disenfranchised and disempowered by external factors and conditions and labelled with characteristics which are beyond their own individual control, both the wider disability movement and society generally continue to squander and waste a unique and valuable resource.

The disability movement needs to ensure that 'minorities' within its ranks are empowered to participate and that their issues are presented as issues for the 'majority'. Organizations such as the Black Disabled People's Group and the Asians with Disabilities Alliance are vital parts of this struggle.

Lesbian and gay disabled people have felt equally marginalized within the disability movement and have experienced damaging homophobia. Disabled lesbians have been politically active for many years but their contribution is rarely acknowledged. They were active within the women's movement of the 1970s, pushing for access in the widest sense. They were key in the formation in the early 1980s of the disabled women's group Sisters Against Disablement (SAD), where they could explore their issues as women and enable them to be more articulate in

the wider disability and women's movements. Against other achievements they developed an access code, which is still used today by many organizations up and down the country. As Kirsten states:

'When SAD started we were accused of being divisive, diverting from the cause. I don't think it did, it gave women an opportunity to rally, express ourselves and if our lasting legacy is the SAD access code, it is a bloody good thing we did it and even though it was a bloody fight, we know that was us!'

In 1989, as a result of feeling excluded and actively silenced within the disability movement, a group of disabled lesbians and gays founded REGARD. REGARD produced a 'Charter of Rights' demanding an end to heterosexism within the disability movement and equal participation for all disabled lesbians and gays who were 'out and proud' within the disability movement. REGARD remains the focus of activity for lesbians and gays within the disability movement, pushing the movement to adopt a comprehensive equal opportunities policy and action plan. As Kath, a founder member of REGARD, explains,

'From such small beginnings, i.e. five disabled lesbians and gay men in my sitting room, we now have hundreds of members, individuals and organizations interested in our work. This is not only validating of our experience and our lives but demonstrates that slowly but surely we are having an effect. We are changing things for the better! There is always more to be done and a better way of including everyone but it is also important to recognize our achievements.'

In this section, we have highlighted the changes which the disability movement needs to make, in order to recognize and respond to minority groups of disabled people. Equally important, however, is the disability movement widening its approach to cover all aspects of disabled people's lives, including issues about relationships, parenting, and sexuality. Although disabled people have been vociferous in their demands for rights, sexual rights have not been a priority on that agenda. It may be that sexual rights are implied in the call for comprehensive civil rights. However, many feel that they have not yet entered into a dialogue about how those sexual rights will be secured. As we have shown in this book,

the subject of sexuality and disability is still largely a taboo area. Disabled people themselves may still feel uncomfortable about discussing sexual rights or sexual expression. As Jazz states:

'I still feel the wider world sees disabled people as asexual and the disabled people's movement is not doing enough about it. It is easier to talk ramps and equal rights and education and things for the common good than to talk about very personal things like sex and sexuality.'

Another respondent summed up the need for society, and the disability movement itself, to recognize sexual rights:

'They should be becoming more supportive and acknowledging the fact that disabled people have sex lives. ..gay or not doesn't matter. ..the fact they have a sex life, and they have the right to have a sex life. To accept the fact that disabled people are just like everybody else. ..we've got our own sexual ideas, fantasies and desires, just like anybody else, and in most ... in all cases, we can fulfil those wishes/ideas if we were just left to. The disability organizations should encourage this.'

Challenging other movements

While it is true that the disability movement needs to adapt and change if it is to be fully representative, it is also the case that other movements and communities need to adapt and recognize their disabled members. Here we will briefly consider the women's movement and the lesbian and gay movement. Many of the comments made might also be applied to the trades union movement, the black people's movement and other areas.

Above, we mentioned the formation of Sisters Against Disablement (SAD). Hearn writes: 'We were fed up with the sexism in self-organized disability movements and even more fed up with the ableism of the women's movement. Our attempts to participate had been accidentally and sometimes deliberately obstructed' (1988: 126). However, the issue of disability and feminism is wider than just access. Lois Keith (1992) and Jenny Morris (1991, 1993a) have written about the conflict over community care: while academic feminists have argued that community care is oppressive to women, who do the majority of unpaid care work,

Keith and Morris have argued that institutionalization is not an alternative, because it infringes the rights of disabled people, a majority of whom are themselves women. Again, Jenny Morris (1991) has written about the potential clash between absolute abortion rights and the need to oppose eugenic screening which eliminates disabled people from the population. Both these issues are not irresolvable contradictions: but they require more dialogue than has hitherto been the case.

In their article 'Smashing icons', Marian Blackwell-Stratten, Mary Lou Breslin, Arlene Brynne Mayerson and Susan Bailey (1988) discuss the political priorities of disabled and non-disabled feminists, showing how there are both links and differences. They make three key points: that being disabled and female is a unique dual status, different from other women; that while non-disabled and disabled women may agree on issues, the solutions may be different; and that disabled women experience 'double' discrimination. Feminist protests against violence against women are an example of differences in practice. While non-disabled women may demand better street lighting, disabled women may be campaigning for, the bus company to operate wheelchair- accessible buses at night: similar problems, different priorities and solutions. We would argue that disabled women need both better lighting, and better accessible transport: women against violence against women groups, dominated by non-disabled feminists, have not recognized the different aspects of disabled women's experience. Elsewhere, Blackwell-Stratten et al show how radical approaches taken by disabled feminists can be of benefit in other women's issues: thus, rather than seeing effective pregnancy leave as 'protective legislation', the notion of reasonable accommodation found in disability employment good practice enables pregnancy provision to be seen as equalizing outcomes for women in the job market (Blackwell-Stratten et al., 1988: 329).

British feminist Nasa Begum has written about the relationship of disabled women to the feminist agenda, highlighting again the different implications for disabled feminists (Begum, 1992: 75):

If, as disabled women, we do not conform to conventional gender roles then the fight to gain access to institutions such as the family becomes extremely difficult, if not impossible.

Although these institutions are considered oppressive by many feminists, the struggle against the family may be different for those of us who are excluded from the outset.

Again, as a previous quotation from Jo shows, arranged marriages may provide access to family life, but contradict women's right to choose whom, when and where to love. Thus feminism and cultural values can result in ideological conflict while providing solutions for individual disabled black women. Begum concludes (1992: 82):

The feminist movement has restricted its thinking to the needs of nondisabled women. It has had difficulty tackling diversity among women, consequently many women, particularly those of us who have disabilities, have been left out in the cold. Feminism urgently needs to address the issue of diversity and in the process of doing this it must learn from the experiences of disabled women.

The collection of essays edited by Jenny Morris (1996), *Encounters with Strangers*, continues this dialogue between disabled and non-disabled feminists.

We have discussed some of the issues around disabled people in the lesbian and gay movement in the previous chapter. Here we will add two points about organizations and networking. In April 1988, disabled lesbians and gays held a National Conference for Lesbians and Gays with disabilities in Manchester, following the inaccessibility of the Legislation for Lesbian and Gay Rights Conference in London in May 1987. Hearn writes about the difficulty of organizing and fundraising for the Manchester conference (Hearn, 1991: 30):

The severely able-bodied community and the straight disabled community virtually ignored our campaign. It was necessary, therefore, to make complete and utter nuisances of ourselves. The pink press snuffled with embarrassment and granted smidgens of coverage.

She described the event for us:

'We had a wonderful weekend with 60 lesbians and gay men with disabilities, it was exactly what we wanted to happen and that event has been the foundation of so much that has followed. I think groups are so important in promoting self-worth and self-confidence and providing a vocal point really for us to campaign from.'

Subsequently, disabled lesbians and gay men formed LANGUID (Lesbians and Gays United in Disability), which focused its attention on the exclusion of disabled lesbians and gays in the lesbian and gay community but was also a consciousness-raising, empowering experience for many disabled lesbians and gay men who felt they did not belong in any community. After LANGUID dissolved, it was replaced by REGARD, which has actively challenged the disability community to accept disabled lesbians and gays: it was formed following the Cap in Hand Conference on disability representation where lesbian and gay issues were raised, but ignored by the majority. REGARD has become the focus for lesbian and gay activity, and for engagement with the wider disability movement.

Common concerns and agendas are being addressed by diverse organizations. The UK Coalition of People Living with HIV and AIDS has strong links with REGARD. The public workers' union UNISON has both a lesbian and gay and a disability committee, and again has strong links with REGARD. Representatives from these committees raise issues that are relevant to disabled people, lesbians and gays, and people with HIV and AIDS, and obtain the union's support or persuasion to ensure positive change. An ongoing example is the support offered by UNISON to achieving anti-discrimination legislation for disabled people. Another is the annual summer Pride celebrations, the major event of the lesbian and gay calendar. For years, disabled lesbians and gay men have insisted on being part of this event. Not so long ago, the number of disabled people on the Pride march could be counted on one hand. Now, with ongoing dialogue between UNISON (a major supporter of Pride), REGARD, the UK Coalition and public forums, the numbers of disabled people have swelled enormously. This increase in participation is partly due to solidarity, but because access is now on the agenda we can actually participate in the event and celebrate our sexuality as disabled lesbians and gay men.

Disability and HIV / AIDS

Two of the disabled people in our research had discovered that they were antibody-positive. We also spoke to two other men who were HIV-positive, one of whom has AIDS. Other disabled gay men in our research had worked as volunteers or professionals in the HIV/AIDS field. Jeremy told us of his time at Gay Switchboard in the early days of the virus,

'I helped organize the very first meeting between New York Gay Men's Health Crisis, and Gay Switchboard, they did a seminar for us. We knew about AIDS and how it was transmitted, but no one told us how to get over talking to people on the phone who were dying. What do you say to someone who says "I've got AIDS" ...I got burnt out very quickly and found it very traumatic.'

Kirsten Hearn has suggested that the epidemic has the potential to change the role of disabled people within the lesbian and gay community (1991: 37):

It could be said that disabled lesbians and gays have gained because of AIDS. It has forced the gay community to recognize human frailty, and to start living at a rate and in a manner that will include all of us. But there is still this 'It can't happen to me' attitude Those who do recognize AIDS as the biggest threat faced by the gay community for many years may still not understand the relevance of positive action on the disability front. Like AIDS, disability can strike out of the blue. A car smash, a sudden illness, a knife attack or HIV – all can cause disability.

The fact that the lesbian and gay community has to change in order to its members who have *HNAIDS* means that it will also examine its relationship with disabled people (Hearn, 1991: 38):

Unless the community welcomes all of us, irrespective of our abilities and disabilities, irrespective of our race, gender, class, size or age, it will not be providing a safe and welcoming

environment for those sections of the communities whose participation will be threatened because they have AIDS.

In this section, we will explore the parallels between HIV/AIDS and disability; then we will look at the readiness of people with HIV/AIDS to identify as disabled, and the willingness of disabled people to work with people with HIV/AIDS. Finally, we will look at some of the campaigning opportunities that an alliance would offer.

HIV/AIDS is a medical condition, yet its implications are social and political. People with the virus experience stigmatization and prejudice. This may include violence, hostility, discrimination in employment and housing, and other forms of exclusion. Although they spend only 10 per cent of their lives after diagnosis in hospital, they are regarded as sick. As the condition continues, they may become dependent on benefits, and they have more contact with health and social services. Often this involves professional domination, silencing the voice and views of the person themselves. All of these experiences parallel the experiences of disabled people (Shakespeare, 1994).

People with HIV are not ill, and do not suffer physical restriction. But they have a similar status to other people with hidden impairments: being open and experiencing prejudice, or having to manage information and risk exposure. People with the opportunistic infections which constitute AIDS may well develop impairments, including weakness and fatigue, forms of visual impairment, pneumonias and cancers. Often they have to use wheelchairs and other aids. All these experiences parallel the experiences of people with impairments.

Given the shared experiences, it may be surprising that most people with HIV / AIDS are not prepared to identify as disabled. However, we argue that this is because disability is defined in terms of the medical model, and is stigmatized. People with HIV/AIDS have stressed that this is a social experience, and are unwilling to identify as victims, invalids or dependent people. However, as we have shown in this book, disabled people have themselves rejected this approach to disability. The social model of disability is both appropriate to those living with HIV/AIDS

and does not undermine their determination to be accepted as survivors living positively.

Generally, disabled people are not yet ready to recognize HIV or AIDS as an impairment and embrace people living with the virus as part of the disability community, but there is a growing awareness and a gradual change in perception of people with HIV/AIDS. Elizabeth said:

‘HIV/AIDS shouldn’t really be a disability issue but I suppose it is.’

A reluctance to accept this new impairment group may be anxiety about how the disabled community is viewed by the rest of society or it may be about resources. Some disabled people are angry at the benefits and services available to people with HIV and AIDS when they are struggling without essential aids and adaptations and living on poverty-level benefits. As Sara states:

'Unlike other disabilities, people with AIDS get a lot of support. All gay men and lesbians who have disabilities should have the same help.'

Others can see the parallels that exist between disabled people and people with AIDS, as Patrick states:

'Some people with AIDS require support, personal assistance, and resources to continue living their lives. This is like people who acquire a disability or have a disability that becomes more "prevalent".'

Jazz believes people with AIDS have a harder time than other disabled people because of prejudice and ignorance:

‘It's difficult, it's an epidemic type thing as opposed to ... if I touch you, if I kiss you or if I have sex with you, then I'm not going to die from it. There's this whole myth that people with AIDS are evil and go around trying to give others AIDS [...] don't see the media moralizing about people with brittle bones (my impairment) going around and having sex.’

As the virus is transmitted sexually, HIV has forced service providers to accept that disabled people are sexual beings, and this realization has

often resulted in a panic to provide safer sex education and appropriate services. People with HIV or AIDS are still struggling with their identity as 'ill' or 'disabled' people. As we have explained earlier, with so little positive imagery of disabled people, and negativity around disability, it is not surprising that people find it difficult to identify as disabled. However, as disabled people become more militant and vociferous, and as people living with HIV/AIDS recognize they are competing for the same services as disabled people, links are being made and alliances forged.

The UK Coalition of People Living with HIV and AIDS is now part of the 'Rights Now!' campaign for anti-discrimination for disabled people, including people with HIV/AIDS. They have disability rights on their agenda, and gradually people within the disability movement are recognizing that HIV is a disability issue, as Jenny states:

'We need to make stronger links but we also need to be patient. I want to drag them (people with HIV/AIDS) into the twenty-first century, as these people essentially have a non-disabled identity. They use language like "victim" and "sufferer", language I have been trying to get away from and am not comfortable with.'

The UK Coalition of People Living with HIV and AIDS is an organization run and controlled by people living with HIV and AIDS. This is an important departure from the vast majority of AIDS organizations (like the history of disability organizations), which are controlled and staffed by people who do not have HIV or AIDS, and is part of the move toward self-organization and autonomy.

There has been a considerable amount of liaising, sharing experiences and collaborating between the UK Coalition and REGARD. This was not so much because many people with AIDS are gay men, but more to do with the work REGARD had done on making links between the communities, based on what had gone before in America. REGARD aware of the important contribution of the AIDS lobby in achieving rights for disabled Americans in the form of the Americans Disabilities Act. However, there is a certain amount of frustration at what appears a

slow pace of politicization of people with HIV and AIDS. As Jenny states:

'I'm not patient, I want to say just get on with it, that's because I want them to get on with it. There is strength in unity and this would be so powerful but not at the expense of other people's agenda. It's about thinking there's a common identity amongst people with AIDS but they're a group of individuals, straight, gay, lesbian and they just happen to have one thing in common which is HIV and AIDS. ..and presumably a common objective. That's it, so why should they have anything else in common!'

To conclude, an alliance between disabled people and people with HIV / AIDS would offer advantages to both groups: first, a shared voice in demanding civil rights and better services; second, the experiences of self-organization and social model approaches learnt in the disability movement; third, the professionalism, treatment activism and resources of the HIV/AIDS lobby.

Changing ourselves, changing the world

As we have argued in this chapter, there are two key areas of change. First, political action to ensure civil rights and social integration. With comprehensive anti-discrimination legislation should come an end to barriers, an end to segregated education, and the opportunity for disabled people to move out of the margins and into the mainstream of society. Access to jobs, money, leisure facilities, and the other parts of life will enable disabled people to be more fulfilled as individuals and as sexual beings.

However, civil rights are not enough without widespread education to challenge discriminatory values. Beth talks about the changes she would like to see in this area:

'I believe that sexuality and sexual politics are inextricably linked with the politics, values and attitudes which shape our society. There is a long history of oppression of disabled people which influences modern society. Freedom from sexual restrictions for people who are disabled

can only start to be possible as society as a whole begins to accept that weakness and unacceptable practice lie with it, not with individuals. I would like to see those who have power being made to confront their prejudices, but believe that this will only happen when the weight of public opinion moves to make appropriate demands. I am sure that my sexuality will only be accepted by the majority when I feel that I belong as I am.'

For centuries disabled people have been locked away, hidden from view, separated in segregated institutions and silenced. Centuries of treatment as second class citizens, viewed by the rest of society as pathetic, tragic, brave or monstrous and predatory, will not be overturned overnight. As Daniel states:

'We need to be part of the fabric of society. We need to be in books, on TV, in films in work, and in the family. What are the key life activities?

...work, family, leisure, we need to be everywhere!'

The other means of change, perhaps more fundamental, but linked by cause and effect to the experience of discrimination, is personal change. Each disabled person who wants a better life, rich with meaning and opportunity, needs to feel they are deserving and capable of occupying that new space. The low self-esteem typified and described by so many disabled people must be addressed if we are to take our rightful place everywhere in society. As Ruth says:

'I think empowerment of disabled people is probably the most important thing in getting people out of institutionalized situations whether it is in the home or in an institution, because that fucks up your sexuality more than anything else. Also, not seeing ourselves as victims, as it is very difficult to have an independent sexuality if you see yourself as a victim.'

Many disabled people who adopted a negative self-image based on the views of family, friends, and society at large have begun to challenge long-held views about themselves and are beginning to be proud of who they are. Proud to be disabled, proud to be a survivor, proud of a positive identity. For many adopting an identity as a disabled person has been a

'rite of passage' into a more enlightened and positive future. As Julie explains:

'My claiming an identity as a disabled woman has had a huge impact on my life. I am disabled by institutionalized prejudices and societal attitudes not by my own abilities. I am proud to call myself a mental health survivor. Because I have survived in spite of those obstacles and prejudices and because the very word speaks of hope beyond the despair of psychic pain.'

Our perceptions of ourselves are not set, but are changing and changeable. Some of us are taking very active measures to perceive ourselves in a more positive light by way of workshops, individual therapy, co-counselling, etc. Expressing ourselves through the arts is a growing movement of positive exploration. Disabled people are training as therapists and counsellors, but are informing the content and method of that training so that disabled people can avail themselves of help which is not based on negative assumptions about impairment. Others are developing courses which provide insight and work toward the empowerment of disabled people. A whole range of changes are taking place which demand a re-think of the negative myths and assumptions about disabled people and presenting new perspectives which disabled and non-disabled people alike will find challenging.

Part of these changes are about changing our perceptions of desire. Society still tends to accept' unquestionably that 'beautiful' people are, by and large, young, pretty, and healthy, despite the fact that most of us aren't like this or don't stay so for very long. It is accepted as incontrovertible that the more one looks like a muscle-bound god or goddess, the more beautiful one is. Clearly, this is not 'natural' or inevitable. We aren't necessarily born to desire only twenty-one-year-old blond bombshells! Desire is conditioned by society and by our personal experiences. Very simply, if we are brought up to fear disability, it is hardly likely that we can find disabled people desirable. Similarly, if our culture and media promote 'ideal types' and gives them status and power, then these images and ideas bury very deep in our sub-consciousness so that we find ourselves, at least in part, reflecting what society accepts as 'beautiful'. Of course, no one can expect just to give all this up overnight

and find everyone desirable (fabulous as this would be), but we can at least begin to understand how this oppression works and rethink some of our assumptions about ourselves and others (Gillespie-Sells and Ruebain, n.d.).

Disabled people are beginning to challenge the notion of 'beauty' and exploring the reasoning behind choosing disabled or non-disabled partners. As Paula explains:

'The kind of person that I will find attractive is somebody that I can have a decent conversation with, who makes me laugh and if that's not happening I won't be there.'

She goes on to say disabled people are beautiful and we do not need anyone to reconstruct us. Daniel describes the changes in his thoughts and feelings, about his disabled friends.

'I now count my disabled friends as some of the most important, which is diametrically opposed to how it used to be. I now feel energized and slightly invigorated by being with them, instead of feeling slightly disgusted by them.'

He goes on to talk about the possible benefits of a disabled partner.

'Part of me would like to get involved with a disabled person because I think this would be good. And whatever else we did, like having good sex, or fall in love, we might also be good for each other in our continuing journeys, learning more about ourselves.'

It is important to highlight the ways in which changing society, and changing ourselves in these ways, have implications which reach beyond the six million disabled people in Britain. Making society barrier-free and more accepting of difference will enhance the lives of many people who do not come into the disability category: older people, children and their parents, people with temporary illness, and other minority groups. Similarly, challenging notions of beauty and normality has the potential to release others from the tyranny of our contemporary obsession with health, fitness and good looks. We know how important this is from the

feminist literature on dieting and weight, and studies of prejudice against older people. Disabled people already form the largest minority group in Britain, but the agenda for change suggested would enhance the lives of the majority of the population.

Penny

When I was young and wilfully impressionable, I read Erica Jong's *Fear of Flying*, and became obsessed with the idea of the zipless fuck. I spent my post-school years searching for my own wild sexual encounter, the wonderful chance happenings of instant hot desire, romantic inclination - and absolutely no emotional attachment. That it never came to pass (as in the novel) demonstrates more how the heedless erotic imagination can sometimes get stupidly carried away with itself, rather than a zipless fuck being seen as a ridiculous notion for someone with my physical impairment to even dare think of.

Because no, I see my limitations only as parameters: my normality, m~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. I am often left feeling surprised -and smug -when I hear my non-disabled female friends bemoan the stale approaches of lovers, the tedium of flopping into the same sexual position, the lack of open and honest communication.

Without the latter, I wouldn't have a sex life. Because I can communicate with my lover, I can say 'Let's fuck on the dining table right now': I know he will be delighted at my request and be guided by what I need from him. My lover is strong and can turn and twist me with expert hands. In the beginning, my instructions of how I wanted - how I needed - sex to go a certain way would be part of the fun, because, despite the passive, asexual label society expects me to wear, I enjoy being dominant. I still give commands, but now with total security and endless humour.

So I say. ..put the pillow on the table. Lift me up so I can be laid forward, right over it. The pillow is soft and the table is hard. I like this. Penetrative sex is good this way if you need a lot of support. The table takes all of my weight and I am entered from behind. It's good for hot, frantic sex too. I like that sometimes because it makes me feel very strong - again belying the label of fragility my medical condition gives me. So-called 'doggy' positions are immensely satisfying for deep penetration and, with enough pillows and the like, very comfortable.

Another favourite is where I am bent over something on the bed itself, which is small enough to allow for my clit and nipples to be caressed.

There's a rear-entry 'lap' variation too, which is good for quick, lusty, 'public' sex. Even if full penetration isn't always possible, enough friction can be attained to get to orgasm. I will sit on my partner's lap facing away and leaning forward as much as I can, with him holding me. As I usually end up leaning my full weight back on to him, I feel immensely sexually powerful in this twist on the 'woman-on-top' position. Just give me a good disabled loo, and I'm lost to it!

If I want to see my lover's face when fucking, there's many gratifying variations on the normal missionary position. I get him to put his legs around me, and I open mine a fraction. We both get very aroused by just rubbing together this way - his stiff penis runs tight between my legs, over my clitoris. It is both teasing and exciting. Penetration is possible this way, and a pillow under the arse helps. ..but it is not so easy for those of us who have grown tubby bellies. Sometimes I part my legs to my own comfortable level so that my lover can put one leg and his penis" between them which is very enjoyable, a tight constricting tease of pleasure.

If I am to almost achieve my zipless fuck, a snatched moment of intense lust in some random, excitingly inappropriate setting, I believe it will be done this way: I lie on my back (on the bed or ground) and with the barest minimum of clothing undone, my legs are lifted up against his torso, so my feet are just over his shoulders, again, totally supported. Standing or kneeling, he can enter me from this position, or rub himself up over my clitoris. If I keep legs either side of his head, then his hands are free to fondle my clit and breasts. Sometimes I will move my legs further apart and slide them down under his arms and he will hold the weight of them, still keeping them raised enough to hold the strain off my hips. I relish this position because I have a desire to clasp him hard with my 'feeble' limbs, something I have not yet worked out within my own parameters. But I will.

For long, undulating fucks of suspended drawn-out arousal there is 'spoons'. If anything in my body is remotely tetchy, then spoons will

heal. I lie down on my side and my lover lies behind me. Penetration and caressing is simple. Movements can be very soft or more urgent depending on our mood. A variation for harder sex is when my lover puts his top leg right across mine on to the bed and 'locks' us into position. I roll forward slightly, and the constriction created is very pleasurable for us both.

Of course, sex isn't just about instant penetration and quick orgasms. Sometimes I like to play for a long time. A disabled female friend introduced me to vibrators at an early age and now I would be lost without my buzzing buddies. My hands tire easily? My fingers get stiff? Do I care? No, I let battery power take over. We integrate them into our games, so I can caress and massage my lover (and myself) at my own comfortable level, to my speed, using soft hands, and then my tireless powered-up friends.

Oral sex I approach with relish. I turn the fact that I am prone to jaw cramps and stiffness into a teasing game. I give head and rest, head and rest ... then I receive an oral blessing myself that drugs and heals me better than any medication I have known. I give myself up totally to the gentlest, yet most focused, of sensations.

For me, sex is about pleasure, humour and respect. It is with these factors in mind that I approach any seeming 'difficulty' my impairments present me. Of course, there are techniques and positions I will never manage to do. But I know this is true of most people, along that huge scale of physical variety that in reality exists in human beings. Some activities I choose not to do, because have no taste for them. This is as it should be. But I also know my open attitude to my sexuality, arising because I am a disabled person, often defines sex for me as a much more celebratory and explorative experience than for many non-disabled people.