

Chapter Six (in *The Sexual Politics of Disability: Untold Desires*, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 153-181)

Six

Double the trouble?

Introduction

In her article 'A proud label' (1994), Jenny Corbett explores the relationship between disability politics and gay pride, discussing parallels such as experiencing stigma and coming out, which have informed the current study. She makes the point that while lesbians and gays are defined by their sexuality, sexuality is seen as non-existent in the lives of disabled people. Disabled people are totally defined by their impairments. Clearly gays and lesbians are more than their sexuality, and disabled people are more than their impairment. Equally, there are disabled lesbians and gays in large number, and there is a danger of neglecting this, in the process of drawing parallels between the two experiences. In this chapter we will discuss issues specific to lesbian, gay and bisexual people: because we have also been concerned to include lesbian, gay and bisexual accounts elsewhere in the book, there will inevitably be some overlap. Given that there has been hardly any discussion of these issues to date, we make no apologies for duplications here.

Sexuality and disability

While we have argued that disabled people are all too often seen as asexual, it is also the case that there are heterosexist assumptions that disabled people cannot be lesbian or gay. Older literature has a clear homophobic tendency: for example, the arguments of Isabel Robinault that 'healthy masturbation' is a better sexual outlet for disabled people than 'sexually inappropriate responses, i.e. homosexual contacts' (Robinault, 1978: 28). The same author uses her prejudice to provide an entirely unsupported argument against inclusive education: 'An unrestricted environment may inadvertently direct some disabled youngsters away from

heterosexual responses, which is another reason for caution against massive, uncontrolled mainstreaming of impaired youth into unprepared environments' (Robinault, 1978: 60). This bizarre approach to the issue finds an echo in an earlier article in *The Lancet*: as one of a series of short pieces about different impairments we find a first-person account by a lesbian woman (*The Lancet*, 16 July 1949:128). Until the early 1970s, the American Psychiatric Association classed homosexuality as a sickness. As late as 1980, the International Classification of Impairments, Disabilities and Handicaps was still defining homosexuality as an impairment (WHO, 1980). On the one hand, therefore, we find that disabled people cannot or should not be lesbian or gay: on the other hand, it is suggested that people who are lesbian or gay are themselves suffering from an impairment.

The case of Sharon Kowalski shows the prevailing prejudice against disabled people expressing 'deviant' sexual choices. She was an American lesbian who became disabled after a car crash. Her father was awarded legal guardianship, and subsequently denied access to Sharon's lover Karen (Appleby, 1994: 21)

This was in spite of much evidence from Sharon's medical staff that Sharon's progress and well being improved when Karen was there. Sharon herself had communicated through various means that she wished to return with her lover to their shared home and life. This request was refused by her father.

While this case ended successfully, with victory after long legal struggle, it shows the obstacles facing disabled lesbians and gays, especially people who are doubly vulnerable - young people for instance, or people with learning difficulties, or in this case people with profound impairment - because they are not seen as independent or capable of choice.

In our survey, Kit talked about the difficulties of claiming your sexuality, as a disabled lesbian:

'I actually think being a disabled lesbian is a very ... it's a struggle, I don't mean that it's a struggle in that I don't want to be a disabled lesbian, it's a struggle in that you are completely, you are completely insignificant and denied any identity or importance.'

She picked up on the common perception that disabled lesbians were not seen as having chosen their sexuality, but instead that their sexuality resulted from their failure to be real women:

'You are not a real woman, so the only person that you can find to fall in love with you is another; woman.'

Many of the disabled lesbians and gays we spoke to were people who had become disabled later in life, often some time after having come out as gay. Clearly this highlights the differences between disabled lesbians and gays, despite the common experiences of double oppression. In the next section we highlight issues of identity, while exclusion and prejudice will be explored subsequently.

Becoming gay or lesbian

In the first chapter, issues around identity were discussed. Here we will explore the specific feature of disabled lesbian and gay identity, and the interrelations between sexuality and disability. Some of these are clear cut. For example, Kirsten, a blind lesbian, argued that the inaccessibility of information to blind people meant that alternative sexualities and sexual options were not available. It was being involved in Women's Tape Over, a women's tape magazine, which put her in contact with the coming out stories of lesbians, with which she was able immediately to identify. For her, coming out was a liberatory experience:

'The sheer joy of coming out as a lesbian was so important to me, I'd come out to everybody, the taxi driver, the butcher you know, I was mad, absolutely mad.'

Lesbian, gay and bisexual disabled people report that gender, disability and sexuality interact in different ways. For Daniel, coming out as disabled was different from coming out as gay:

'I feel it's been a second coming out to me, and far more important than coming out as gay. I had never been "normal" as a child, so coming out [as gay] was just another not-normal thing to do, and didn't present me with

any problems as such. If you are not expected to have a normal sexuality or to be a regular guy, being gay is no great shakes.'

Another man, who had had polio as a child, had managed his gay identity fairly straightforwardly, had been very out and open and worked as an activist in the gay scene. However, it was only when a non-disabled friend pointed it out to him, that he realized he had never come out' as disabled. He had projected his feeling of difference into his gayness, and denied his physical experience. Both these men found it much easier to acknowledge their sexuality than to acknowledge that disability. However, Jo, born with her impairment, suggested the physical 'deviance' was viewed differently from sexual 'deviance':

'As far as disability is concerned there is an acceptance about disability, a political understanding - even if it is crap and patronizing it is acceptable to be disabled as it's basically about caring! You can influence disability, you can make an impression on how people see it and you ...whereas being lesbian or bisexual is about perversions and it is not acceptable. So one's an acceptable difference and the other is just disgusting.'

Patrick found that being able to deal with one 'difference' helped in dealing with the other:

'I think in a way as I work through the business of being gay it's helped me in trying to come to some kind of image or idea about being disabled.'

For others, coming out as disabled enabled them to come to terms with their sexuality, and perhaps freed them from expectations and pressure to conform. Kit told us:

'Taking on the identity of a disabled person was absolutely vital in coming to terms with my identity as a lesbian ... I think, looking back on it, I think I've been a lesbian for ever, but I had no contacts with that, I had no way of dealing with that, and every time, I know now, that it came into my head, and I would push it away say, go away, go away, it was so unbearable.'

Kit's coming out process was long and complicated: to start with she had an impairment, but didn't define as disabled. Then she started having a

relationship with a woman, but didn't define as a lesbian. Then she came out as disabled, and finally she came out as a lesbian. In each case, it was about moving from an individual to a collective identification, and it was also about an inevitable process of becoming 'who she really was':

'I had plenty of opportunity to have boyfriends, but I couldn't do it, no matter how much I wanted to be the same as everybody else, more the same, I just couldn't do it.'

Kirsten also felt the two processes were similar, despite the fact that her impairment was always! overt in ways that her sexuality was not:

'Because in 1981 I did come out as disabled, and very soon after that in 1982 I came out as a lesbian, and I think without one there might not have been the other in some ways. [...] for a few years I had this complete flirtation with visibility as a disabled lesbian, and it was dangerous, I was really stupid, because I ended up not being taken seriously for who I was, because I was having to say blind lesbian, blind lesbian all the time. People couldn't cope with that. They can cope with one identity, they cannot cope with two, and they could not cope with that combined identity of who I was, which I think is very interesting.'

Frances's comments show that disability and sexuality have different significance in different contexts:

'Both are equally important to me as a politically aware disabled lesbian. However, it is more likely that I am perceived as a disabled woman first, since I do not always come out as a lesbian. The lesbian community is not particularly aware of disability issues.'

Others, because of a feminist standpoint, or a politicized gay identity (for example Dafydd), found that becoming disabled later in life was eased because they could draw parallels between these identities and their new experiences as disabled people.

Julie, a mental health system survivor, was aware of the interrelation of her gender, sexuality and 'madness':

'I am oppressed as a woman in this society and treated even less favourably as a lesbian woman. But as a "mad" lesbian woman I am treated like the ultimate threat to patriarchal society - a scourge in the community or a contamination (which can be OK at times because I get a seat all to myself on public transport). Am I mad because I am lesbian in a heterosexual world? I mean, it's dangerous so I must be mad to choose it. Or am I lesbian therefore I am mad, i.e. it's a mental disorder or a sickness? Or am I lesbian because I am mad, i.e. I can't think straight? These parts of my "being" are so interwoven that I can't separate strands. I'd say my madness is more frightening to others, though.'

There were different opinions from respondents as to how far their and sexuality interacted. For example, some spoke freely about desiring a cure from their impairment, but resisted the suggestion that homosexuality should be 'cured', for example Michael:

'As far as I am concerned, have been disabled all my life, but haven't been gay all my life. But just like being disabled, I have adjusted to it. I've adjusted to being disabled because I have had to adjust to being disabled, because I wasn't given any choice in the matter. I suppose if the truth be known you don't have any choice about being gay or straight, it's just ... it's not a state of mind as some people would have you believe, as I said earlier, it's part of you. You are not treated any less as a person, I think, if you are gay, because it's not something physical. Being disabled obviously to some people is physical, i.e. the fact that I'm in a wheelchair and a lot of people don't see me, they see the wheelchair, so really that is the state of mind of how people perceive me, and a lot of people haven't the foggiest idea that I'm gay.'

Michael felt that his disability dominated his identity because he had no possibility of concealing it: his sexuality he could choose to disclose or not.

A number of people in our research identified as bisexual, which sometimes involved feeling excluded from both straight and gay communities. Jo said:

'Bisexuality implies promiscuity, it says I'm not one thing. I like me and I like women. ..I may go with both at the same time. I'm twenty and I haven't got a lot of experience, so I don't have the experience to back up the ideas.'

Disabled people often find themselves on the margins, a common experience for bisexual people, and bisexual disabled people have argued that it is hard to achieve a sense of identity and community where there is no one place that one belongs. It is interesting that there are many role models for bisexual disabled people from history – Alexander the Great, Julius Caesar, Lord Byron, Cole Porter, Montgomery Clifton Frida Kahlo and Sarah Bernhardt for starters -when there is little room for bisexual disabled people in contemporary society.

Physical exclusion from the community

The dominant values of society are heterosexual ones, and prevailing attitudes to same-sex relationships are very negative. Social institutions such as the family, employment, the media, are inhospitable to, and often extremely hostile to, lesbians and gays. Given this situation, the lesbian and gay community - comprising the commercial 'scene', political and campaigning groups, support groups and helplines, and other social networks - is a vital resource. For those who live in rural areas, or away from big cities with thriving scenes, being lesbian and gay can be very isolating. It has already been shown how young people, who may not have access to the scene or information about groups, or who are prevented from taking part, are at high risk of depression and suicide. It is also the case that disabled people are excluded from the lesbian and gay community, through a combination of physical and social barriers.

Research by Yvonne Appleby (1990) found that the lesbian community was inaccessible to disabled lesbians. In our research, we discovered similar difficulties for disabled people: clubs were upstairs or down steps, they were crowded and smoky and noisy, there were no signers or accessible toilet facilities. The social options of many disabled lesbians and gays are therefore extremely limited or non-existent, and there was consequently considerable frustration and anger, as Michael demonstrates:

'They ought to buck their ideas up basically, and start realizing that there are disabled people that want to come out and the access is shit in most places [. ..] the access to the pubs and clubs is not good and most of them have got one step, a lot of them have got more, MGM for instance I have to rely on somebody, the bouncers or the doormen to carry me up the steps. OK, fair do's if they don't mind doing that but I would much rather make my own way in, I think it's important to have access.

A particular gripe was the poor provision of toilets, as he also told us:

'It pisses me off, toilets are not accessible in a lot of gay pubs and clubs. I've seen ones with wider doors, but not really a specifically adapted disabled toilet, and that is what I would like to see. There are gay disabled people out there, and perhaps that's one of the reasons that they don't come out. I do choose to come out, I have a good time while I'm out, but before now I have had to go home and cut my evening short, because I've wanted to go to the toilet and the best the landlord could offer me, and he actually said that, was a bucket in the other room. I think that's downright disgusting.'

Inaccessibility is as much a matter of attitudes and behaviour as it is of physical barriers, as Ronan mentioned:

'It's little things like being able to go to the lavatory, I mean, you go to a gay pub, and if everybody in the lavatory is having sex, you can't actually piss. [...] I think that in some cases where there are a number of toilet facilities, I think it's beholden on the management to put up a sign saying some people actually need to go to the lavatory for straightforward, functional purposes, and I suppose there's an unspoken understanding that in some toilets some people have sex, but it's really frustrating if you have been dying to pee for hours and you have to queue while there's three people in the ruddy cubicle, and you feel like a spoilsport.'

Dafydd found a combination of bad access and lack of understanding in one Birmingham night club:

'I remember going out with a group of friends, we go and see a show and everyone wants to go to a night club afterwards. I'm in my wheelchair, I'm

really weak this day. I'm saying, I'd love to come out, but I'm going to need a hand, so maybe I should go home because I don't want to impose, but all the people say "We'll sort that, there's loads of us", "This club's got loads of steps, we're talking steps everywhere", "No, no, there's loads of us, we can carry you endlessly round the club", "So don't leave me alone, keep an eye on me because I can have fits". So we get to the night club and they fuck off straight away, I'm sat in my chair in the night club, It's heaving, I can't leave my chair anywhere and they've fucked off. I need to go to the toilet, I had to get my two women friends to go to the toilet with me, and in the process trying to move through the club, this guy is trying to get around me, instead of waiting for me to pass, he climbs on me, literally, puts one foot on my knee, puts another foot on the handle, and climbs right over me thinking that's nothing, I'm just a piece of furniture. But I have say one good thing happened, one friend of mine who's quite sussed, a drag queen, hastily followed and decked him, she's six foot two in heels, that was good.'

These quotations show that there is poor provision for anyone who does not fit in with the stereotypical gay or lesbian needs. On the one hand, commercial imperatives make it unnecessary for promoters and owners to cater to the small (and impoverished) disabled market. On the other hand, many gays and lesbians fail to consider the well-being of others in their own pursuit of pleasure. Zorah describes the responses she has encountered:

'Oh it costs too much to be accessible, and we don't know how to do it. If we made it accessible would any disabled lesbians/gays come along anyway? (Is it worth our while? Do we want to socialize with these losers anyway, we won't fancy them?)'

Kirsten highlights the twin problems of attitudes and barriers:

'But in terms of ablism in the lesbian and gay community, I think that is also present every day, I mean I am not only not taken seriously as a lesbian, the fact is that the lesbian and gay world is very inaccessible to me.'

Social exclusion from the community

Often access issues serve as a pretext for those who believe that disabled people have no place on the scene: ostensible concerns about safety conceal prejudice, as Sara experienced:

'At Heaven I was told that two people must be with me at all times. I said to the man "They'll enjoy watching me chat up people then, won't they, and if I snog someone in the loo (if I can get to it) how will I fit me, the chair and three people in there?" He was puzzled and told me I was a fire risk. I told him I was with ten friends and I doubted they would leave me there if a fire broke out.'

People with learning difficulties like Nigel are assumed to be childlike, and asexual or heterosexual:

'I have been to gay clubs wearing an obviously gay T-shirt, a pink triangle or some gay symbol like that, and the doorman has asked me if I know this is a gay club and do I want to go in still. The assumption is that because I am disabled I cannot be gay.'

Often the person at the door is literally the gatekeeper, as Phillipe found out:

'For example, in Paris quite recently, a door person at the night club, very strong, 100 per cent perfect, good-looking person, deaf people came, no no can't have deaf people, hearing people yes could come in, deaf people complaining, deaf people are neglected, that's just one example.

The result is to filter out those who do not fit in with the stereotypical, gay or lesbian punter, as Daniel makes clear,

'When you go out on to the streets you see a whole variety of people but you go to the gay scene and the Heinz 57 variety has disappeared, gone, there is only variety number one, and I don't know where everyone is. I have an ambiguous relationship with gay men as a constituency. I feel very much a gay man, and I have lovely relationships with individual gay men,

but gay men as a collective group of people I feel very am very ambivalent about, if not antagonistic about.'

Those who do access the scene have either to conceal their impairments, or risk rejection (Hearn, 1988: 50):

I can hide it, when I'm sitting, but only for short periods because I cannot make eye contact and respond visually to body language. I am often thought to be rude, drunk or not interested. Other lesbians with disabilities can't even hide their 'different' bodies even when they are seated. Severely able-bodied lesbians look at us and go, 'Ugh, what's wrong with her?' You only have to go to a disco to realize to what extent lesbians have bought the idea of the slim, agile, symmetrical body.

While gay men are notorious for their body fascism, disabled lesbians have also experienced prejudice, for example Sara:

'At clubs I've been patronized or used as a token disabled person. At parties I've been chatted up when I was sitting on a couch or chair and when people see me getting into my wheelchair they are suddenly called away. Once a woman gave me her phone number and begged me to come for dinner, I said "I'll think about it". When she saw me get in my chair her face fell and she said "On second thoughts, I'm very busy next few weeks", I just said "Yeah, I know" and she was very embarrassed.'

The attitude towards disabled people is often connected with fear of difference, or fear of contamination: Julie argued

'There is blatant prejudice or fear amongst lesbians and gays towards those of us who use psychiatric services or are "mental health survivors". People are generally uptight (and ignorant) re disability issues.'

Some people are particularly prejudiced against those who 'look normal', and have invisible impairments: as Aspen writes in *Bad Attitude* (1994: 23):

Chronically sick and disabled lesbians' needs are often denied, ignored or disbelieved. Belief is crucial and isn't helped by the prevalent idea that we somehow choose to be ill. ... Some lesbians want to 'catch us out'. For instance, a physically impaired lesbian is seen walking, dancing or swimming so it's assumed she could do this 100 per cent of the time if she tried. ... We should question ourselves when we doubt women because denial is a strong attitude in our work oriented society.

In general, disability is too much trouble for most lesbians and gays to be bothering with: disabled people distract from the general hedonism of the scene, as Patrick argued:

'The dominant attitude is we wish they weren't around - "why've they got to come to our pubs, and why do they have to have disabled access and all this fuss. ..."'

It is very common for disabled people to be called troublemakers when they insist on their access rights: for example, there has been an ongoing campaign by the disabled lesbian and gay group, REGARD, and the disability committee of the UNISON trades union for Lesbian and Gay Pride to be made fully accessible. Pride is meant to be the major, celebratory, uniting experience of the year, but many disabled people have found it a nightmare in the past, for example Nigel:

'My experiences at Gay Pride have been mixed but largely unhappy experiences. I have been left stranded without help when I needed it, I had to call upon friends to call a steward for help.'

Thanks to disabled pressure, the event is improving every year. Some disabled people turn up not just to show their gayness to the world but also to make a disabled presence felt in the community, as Ruth indicates:

'I mean, ironically, one of the things I am quite clear about is that I don't think I would have gone on my own to Pride if I hadn't been disabled, because Pride is primarily a men's event, and, OK, it is about expressing the fact that we all exist. [...] It is necessary to make a public statement about our right to be there [...] and I am not sure if I would have gone on

doing it if I was not disabled, I am not sure I would have bothered. It's knowing that somebody will see that there are disabled people there.'

It is a profound irony that the attitudes of many in the lesbian and gay community towards disabled people echo those of the heterosexual world towards lesbians and gays themselves. These types of feelings combined with the generally intimidating atmosphere of many lesbian and gay venues, and the insecurity of many disabled people, contribute to the isolation often experienced by disabled lesbians and gays, people like Michael who talked about trying to meet people:

'It is very hard work, but I think if I don't feel good about myself how can I expect anybody else to feel good about me. I don't feel that good about myself, most of the time I just spend sitting drinking, looking around the room thinking what could be rather than doing something about it. Expecting the mountain to come to Mohammed, that's what I'm waiting for. Yes, I suppose it's equally difficult for other people to approach me, because I find that when somebody does pluck up the courage to come and talk to me, they never really know what to say and a lot of time they are afraid of offending me. However, if and when I do have a one-night stand, it's usually with somebody that I know already, so I don't usually have that problem, but on the occasions that I have met new people, we have both been quite shy and not really known what to say. And then there is the worry of are they being genuine or just playing with my emotions or my disability.'

Many of the lesbians and gays in our survey -for example Michael, Elizabeth, Mark, David and others - felt lonely, isolated, ugly and out of place in the community, and talked or wrote of their longing to find love and companionship. It is undoubtedly the case that many heterosexual disabled people feel much the same. However, first it is difficult to be a minority within a minority, and second it is difficult to be celibate through lack of opportunity in a scene which celebrates sex and which so many are having so much sex.

For those disabled people who form a partnership with a non-disabled person, it seems that some of the stigma attached to disability is transferred

to the non-disabled lover. Kit told us about the attitudes of the lesbian community to her partner:

'It's accepted that she is going to be unhappy in this relationship with me because I am a disabled person and I am deficient in some way. [...] Or that there must be some ulterior motive for her wanting to be with me, like pity or need for control -"I'm needy and dependent on her and she must enjoy that" ...people want to place meaning on it other than we love each other and we make each other happy.'

Kirsten Hearn has written scathingly of the predominant attitudes of the lesbian and gay community (1991: 34):

Issues of equality are not fashionable for the majority of the severely able-bodied, white, middle-class lesbian and gay communities. To them, our disabilities preclude us from having, or wishing to express, an independent sexuality. We are therefore not considered 'proper' lesbians and gays. Most of us do not look, act, move or communicate in what is considered to be a lesbian or gay way. We are outsiders in our own community, and no-one hesitates to let us know that. The message may be shrouded in patronage or ignorance, but we know exactly what is meant by the space created by our absence.

She argues that even the supposedly progressive, political sections of the community are tokenistic, highlighting the way that fund-raising by the community often benefits non-representative disability charities. Hearn and others maintain that the advent of AIDS has contributed to change: while many people with AIDS have experienced the same exclusion and as other disabled people, there has nevertheless been a growth of issues of equality and access.

Prejudice in the movement

Those disabled lesbians and gays who are active in the disability movement often report experiencing prejudice and homophobia: while people may be political, and progressive, about disability, this does not automatically mean that they understand or respect differing sexualities.

Everyone had an anecdote about some appalling experience of homophobia or heterosexism: as Kirsten said,

'I've had women that have sort of withdrawn from me once they found out I was a lesbian and I have certainly had a lot of shit from men in the disability movement, [homophobia] is certainly very strong in the disability world, shall we say.'

or Phillipe:

'The deaf community response to gays is worse than from the hearing [...] One deaf person came up to me and said "Oh, you're a pouf, what are you doing, you ought to be put in a toilet and flushed away, you're full of AIDS, and it would be better for you if you would go down the toilet". I said "Thank you very much!"'

This could be in circumstances of political demonstrations, such as Julie's experience:

'On a Rights Not Charity march a group of deaf disabled marchers refused to march alongside those of us carrying the Lesbians and Gays with Disabilities Banner. They said they didn't want to be associated with perverts!'

Others such as Kirsten experienced it within otherwise progressive disability organizations:

'In terms of homophobia within the disability community, I am currently experiencing this at work, in that a male member of my staff is taking me to an industrial tribunal on the grounds of sexual discrimination and it is based on the fact that I am a lesbian. He says that I hate him because he is a man.'

Notwithstanding the horror stories, it nevertheless seems from our research that the disability movement was not as much of a problem as the lesbian and gay community. At least people could physically access disability events, whereas this was often not the case for lesbian and gay events and venues. BCODP has been aware of problems of prejudice within the

movement, adopting an equal-opportunities focus for the annual conference in 1994, and ensuring that minority groups are represented and consulted. Organizations of disabled lesbians and gays such as Lesbians and Gays United in Disability (LANGUID), and more recently REGARD, have supported individuals and campaigned against homophobia.

Lesbian and gay people have been central to the British disability movement and had a very high profile on many of the early direct actions, and in organizations like the Campaign for Accessible Transport. Ruth told us:

'The same thing has happened with the women's movement, where the dykes were doing all the work, but not getting any of the recognition. I think what happened with CAT and a lot of the early stuff around direct action was organized by women and most specifically by dykes, and the odd gay man.'

Others suggested that more recently direct action has been taken over by heterosexual men.

Practical issues

As well as important features of identity and prejudice unique to disabled lesbians and gays, there are also some experiences and issues relating to impairment and disability which heterosexual disabled people do not encounter in the same way: for example, issues around personal assistance and issues around medical services.

If heterosexual disabled people find it difficult to find personal assistants who will help them engage in sexual activity, the difficulties experienced by lesbians and gay men are significantly more problematic. Lesbians and gay men are still not accepted as equal members of this society. This is compounded by a government that constantly bangs the drum of family values, knowingly excluding lesbian or gay families in that valuing. The carers who are paid or volunteer to work with disabled people are part of homophobic society and bring their views and assumptions into other's homes. As Kay describes

'This particular home help had been with me for two years and I thought we were friends. I began to get less cautious about my reading material and left a book about lesbian sex by my bed. She picked it up and it must have set off a chain reaction. The next I knew she was scrambling down the stairs heading for the front door, mumbling something about Liberace and AIDS and dirty lesbians. She left me high and dry! No shopping done, nothing! She didn't even stop to take her coat or bag. The supervisor had to call back for it! At the time I thought how pathetic, but was quite deeply hurt and shaken and decided I'd have to be up front and tell people. ..but how?'

It is not uncommon for disabled lesbians and gay men to find themselves left high and dry, without essential help, when a carer discovers their sexuality. Others live with a constant anxiety about being found out, or if they are out as lesbian or gay and have an understanding carer, they worry about what may happen when it is time for this person to move on. Decisions about whether to tell a new carer at interview that you are a sexually active person or to wait until they know you as an individual are common amongst disabled lesbians and gay men who have come together to try to resolve these issues. However, at the end of the day although shared experiences and some support can be offered by organizations like REGARD, it is the individual disabled lesbian or gay man who is sitting with a potential carer at interview and has this unnecessary issue to contend with, apart from the usual issues of is the person a capable carer, are they trustworthy, will they get on with my family or friends and so on.

Some disabled people use their personal assistants to make socializing a possibility. This requires a level of intimacy and trust on both parties, especially if the disabled person is intent on finding a potential partner or looking for a one-night stand. There are problems, however, with this arrangement as Kirsten describes:

'Cruising has to be assisted. I have a couple of friends who are very good as cruising assistants. For me it is not about the actual mechanics of sex itself, but about the preamble to that, which is finding and getting to know and stuff like that. If you are seen with someone who is not very good at being a piece of wallpaper at appropriate times, it is a terrible barrier as my minders get chatted up instead of me.'

Gay men told us that their personal assistants were often cruised when they were supposed to be supporting them, which could be distracting and distressing.

Some disabled lesbians and gays, because of their impairments, have considerable contact with support services, such as hospitals and social services. Some people had negative experiences: for example, their impairment was explained by their sexuality, or they were not taken seriously because of their sexuality. Others gave as good as they got, causing no little confusion amidst the institutionalized heterosexuality of the modern hospital, as these anecdotes from Ronan indicate:

‘I was aware of this voice saying “Ronan, are you ready for us?” and there was the vision of loveliness standing there, crinkly brown hair and a square jaw, and blue eyes and long eyelashes, and I found myself saying “You’re gorgeous aren’t you ...”, and this doctor didn’t blink an eye actually, and said “Right, I’m going to have to inject some contrast fluid into you, into your rectum”, I said “Nobody told me about this [...] what else are you going to do?” “I’ll have to inject into a vein as well”, so he put it into my bum and then he said “Is there a vein?” I said “Well there’s a good vein in my left arm, go in there”, and he said “It’ll just be a little prick”, and I said “That’s the story of my life really” (I’m warming to this). And it was lovely, so they give this stuff and the machine did its bit, and afterwards I said “Do I get the snaps?”, because I want to see a picture of this cancer. “They are rather expensive”, the computer is still processing. I said “Never mind”, I said “Do you play rugby?” and he said “Yes I do”, and I said “I thought so”, and he said “How did you know?”, and I said “You fill your trousers very well”. By this time he is pink, I thought they will know a gay man has been here today, and I said “What happens to these pictures?” and they told me the process and he said “You will probably have a scan in about six months”, and I said “In that case Doctor Handsome, like the last witch in Ireland, I’ll be back. [...]

‘But I don’t tell people what it’s like sitting there for hours waiting for the folic acid to arrive [...] and what it’s like sitting in the day unit. [...] You get a couple of leather queens arriving on the ward on Christmas day, covered in gold balloons, my bed was actually a fire hazard they told me,

they said there was so much decoration round and round your bed that it's actually become a fire hazard, and I said "Well, there is nowhere else in the hospital, so I'm making up for it, and as you've told me I'm terminal, can I be a fire hazard for a few more days till I go home?"

Choosing a home

Finding an identity and a community can be particularly difficult for people who are both disabled and also lesbian or gay. Giving space and receiving recognition for both aspects of one's self is often difficult or impossible. The evidence provided above demonstrates some of the physical barriers and social barriers which oppress disabled lesbians and gays.

Particular problems are experienced by those who live in residential situations, or else are dependent on services or carers, and therefore cannot be 'out' about their sexuality because of homophobia. One of Appleby's respondents, Ann, involved in the lesbian support network Gemma, suggested that out of the membership of over 250, only five or six were out about their sexuality: others were 'closeted' because of dependence on carers, residential institutions, or families.

For those who lived independently and were able to express their sexuality, there were a variety of responses when we asked where they felt most at home. For example, many who had gained impairments later in life, especially those who had gained impairments after coming out as lesbian or gay, were more likely to identify with the lesbian and gay community than with the disability movement. In our sample Louise and Ronan are examples of recently disabled people who nevertheless feel more at home in the lesbian and gay scene in which they have spent the majority of their adult life.

Those who experienced congenital impairment, and often those whose profound impairments meant they were denied access to the scene, were more likely to identify with other disabled people. However, some, like Jeremy, had spent their lives denying their impairment, but were positive about their sexuality:

'I would declare myself as an out gay man rather than a disabled man. My identity is firmly out gay. The fact that I am disabled is secondary. I don't know whether that's right or wrong, but that's how I feel. That's because I haven't got a network of disabled friends, I don't know anyone who's disabled really, a couple, but they're just people you meet through work and stuff. I haven't got any lesbian or gay disabled friends. If there was more opportunity I would like to get involved, because that would be really laying it on the line, it would even now be admitting to a weakness. I would like to do something about disability, getting more people to recognize it.'

It is also clear that identifying primarily as disabled is different from identifying primarily as lesbian and gay. The former is chiefly a political identification: it is more relevant to talk of the disability movement than the disability community, as people largely come together for campaigning purposes, not for leisure and lifestyle purposes. While there are disability arts cabarets, and various social events, as well as the meetings and conferences, there is not a broadly based and separate disability scene. Places like day centres are often attended by default, and because of lack of other choices, rather than as a positive decision. The exception to this is the deaf community, where local deaf clubs are a vitally important cultural and leisure resource, and it is entirely accurate to talk in terms of community. Conversely, while there certainly are lesbian and gay political and campaigning groups - OutRage!, Stonewall, Lesbian Avengers, various helplines, etc. - there is also a major commercial scene (mainly for men), and also a fringe of community events (particularly for women).

Other people were able to express their sexuality, but identified mainly as disabled. Lucy, quoted by Appleby (1994: 27), saw herself primarily as a disabled person, not as a lesbian. She felt that because disabled women were seen as asexual, it was easier to deviate from the norm of heterosexuality. While she could choose to be out about sexuality, she had no choice over disability. Even in private she was oppressed by disabling barriers. To her, notions like lesbian strength seemed disablist. While people had experienced homophobia in the disability movement, and disablism in the lesbian and gay community, some felt that the former was less of a problem, or less widespread. Moreover, at least it was possible to gain physical access to disability community events and activities, while

often the scene was totally inaccessible. Kit explained why disability was more immediate to her than her sexuality:

‘What I feel is that I cannot ignore the barriers that face me as a disabled person, because they literally stop me from doing what I want to do, they are very physical ... and I think there is something about having to come out as a lesbian, people don’t assume that you are a lesbian.’

Many people did not feel fully at home in either the lesbian and gay scene, or the disability movement. One of Kit’s anecdotes typified this:

‘... The AGM was on the same night as a lesbian disco, just around the corner, and it was impossible, you can’t miss the opportunity, so I spent the first part of the evening in a cabaret of disabled people with my partner feeling it's very difficult to be a lesbian in this environment, and then went straight to the lesbian disco, I just thought, I was dying to get there, let out that other part of me, and snog my girlfriend in a public place. But then I couldn't be me because as a wheelchair user, as a disabled person, I was patronized, my access issues weren't taken into account, and I felt isolated in the same way.’

Sara, who became paralysed long after she came out, said:

‘I did feel a need to meet other disabled people. I felt I did not belong fully to the lesbian scene any more, but neither did I fit in with disabled heterosexuals. I felt very alone and isolated for the first time in my life.’

Nigel, who has learning difficulties, echoes Sara's feeling of not really belonging:

‘In the gay community there is some awareness of disability, however, I feel I belong to two communities but do not fit into either. [...] I feel more at home within the political disability movement. There doesn’t seem to be any big deal about getting my needs met whatever they are. However, in the lesbian and gay community people can appear scared of me. They are scared because I speak my mind and can be bitter about the way I'm treated. I'm the "crip with' a chip" on my shoulder.’

Jenny felt let down in the gay community, where she expected to find acceptance as a disabled lesbian, but found prejudice: similarly in the disability movement, seeming acceptance did not equal real awareness or recognition.

Many respondents told us that they felt most at home with other disabled lesbians and gays. Here it was possible to relax, and to feel safe, with others who understood both aspects of their identity: it was not necessary to explain matters, prejudice was not such a problem, and experiences could be shared and compared. This was felt by many to be an empowering and validating space, a time to be oneself, to feel at home. Ben was a well-adjusted out gay man when he developed his impairment:

'I remember it was about nine months before I met another gay man in a wheelchair, another wheelchair-using gay man, it was just nice to see another gay man in a wheelchair and to be able to talk about it ... I have got two wheelchair-using gay friends, and it's just such a different experience going out with them, shopping, clubbing, and being on the right height and how people respond to us, it's just there's a lot in common, it's very bonding, it's important, it's important to have access to people with similar disabilities.'

Meeting other disabled people may be more or less straightforward, but finding a home and making spaces where disabled lesbians and gays can celebrate their identity is still a struggle. As Kit said:

'I think we have to create our own place, and that feels hard, when you have got very little energy, when I'm feeling in my down moments, I just feel very, very, angry that there is so much rhetoric about equality.'

It is important to realize that even other lesbian or gay disabled people may not fully understand one's issues and experiences, if they do not share the same impairment. Kirsten said:

'I feel very at home with disabled lesbians and gay men, although I have problems with them as well, like lack of understanding about my disability and blindness, which kind of pisses me off seriously'.

For people with other impairments, it may be that the community of those who share sexuality and impairment is fine for socializing, but bad for forming relationships, because it is too small: everyone knows everyone else, and there is consequently little privacy. Phillipe talked about the way that deaf gay men had relationships outside the deaf community, because the deaf gay community was small and full of suspicion and gossip:

'Now if we did some research on percentage in Britain, deaf lovers with deaf lovers, there wouldn't be very many because they are all suspicious of each other, such a small community, want to see what happened, what went on with their other lovers, it would get passed round the deaf community, it would be very bad, so there's a lot of suspicion goes on within the deaf community so that you can't really get together with another deaf person. If you go with a hearing person, if they tell it doesn't matter, it's a hearing world, there are so many other people there, but deaf gays is a very small number.'

When some of the limitations and difficulties are accepted, it is also important to stress the ways in which many lesbians and gays do succeed in finding a home and creating a community around which they can feel strong and supported. Another anecdote from Ronan conveys some of this sense of family:

'I was still in hospital, there was a guy from the Hasidic community in a bed across the ward from me and his family came to see him every day and there was obviously a very close family, and they dressed beautifully, and it was around New Year and they came to see him, they walked about five miles to the hospital because it was Shabas [Sabbath] and they walked home again, so it was a ten miles walk, in December.

'I said to him the next day "Joseph, I thought that was lovely seeing your family last night, you are obviously very proud of them, and they looked absolutely gorgeous because they had their best clothes on", and he said "Yes, yes, yes, but you have a family too, I've noticed. Your family is very different from my family, but it's obvious they love you very much.'"

Dafydd

I became disabled about five years ago. I started having seizures of some sort, and then two years ago, after a particularly bad season of having seizures, I started to get physically weak, and those two worked together, like, in different ways. I still don't have a clear diagnosis. I use a wheelchair.

In terms of my identity, as well as being gay and disabled, it's important that I'm quite political: I always have been quite political about being gay, quite lucky in a sense that I feel quite happy about being gay, because of the way my parents brought me up. I came from a working-class background, both my dad and mum's family are miners, and I grew up in a small house in Staffordshire where most of the men from my family, extensive family, worked in the pit. It was a very masculine culture.

I had a very squeaky voice at school, there was something not quite right with my voice box, so I would talk in a high camp voice, so I always got abuse at school about being a fairy: I didn't fit in with the standard of what it is to be a boy, a lot of that happened at school. I think at this time, because I didn't know any different, I just assumed this is how lads treat each other at school, the way it is: like you get the piss taken out of you constantly, beaten up too, kids could do that all the time.

It's funny, because although I'd been called gay, it wasn't until I was about thirteen that I started to feel like I didn't quite fit in, and I hadn't put my finger on it, I just didn't know why. So I was a very keen cyclist, in this forest which is just out of town, I was just walking through the woods with my bike, and this guy binged his dick out and said 'Do you want to mess with this?', 'Well, I'll give it a whirl ... ' He was wearing overalls and stuff, like a mechanic, he was really sexy, and then halfway through I ran off, I was really terrified. [...] Then I spent a year going back. I didn't realize it was cruising ground ... so I had loads of sex with older men, and then afterwards I didn't think about it, it was too awful. I couldn't even start processing it, but then, say sixteen, I stopped having sex with men, I started thinking about who I was and what I wanted. Basically, what it was, I knew, I had a quite together upbringing from my parents, they were really sussed, so I knew that what I really wanted was a relationship with a

man, not just sex, I actually wanted to cuddle, to kiss, and to go out, to be recognized as having something good, public affirmation or a relationship, all that stuff.

Then I got really depressed because I realized it wasn't feasible. I knew very clearly from my abuse I'd suffered at school. It got particularly bad around about fifteen. I got spat on on the way home, nearly every night. I don't remember a lot of that, my mum helped me. I remember at Christmas when I saw her, she helped me remember some of the stuff that went on. My parents just perceived me as different, but that's just Dafydd, that's the way Dafydd is, they loved me in those terms.

At school it had always been boys, girls, and Dafydd, in a sense. I had really good sex education at the age of eight in this project that was at my junior school, and we would basically give sex education lessons in the sixth form in a very informal way, like boys would ask me like, about women's bodies and stuff, and so I would talk about clitoris and clitoral orgasms, vaginal orgasms, it's important to focus on foreplay, telling straight lads how to have it off with women. I knew more about it than they did, so it was fun. They needed something from me, so that was good, because it was like acceptance, then, of my role, because they needed something from me, they needed knowledge. The girls conversely would ask me things about boys' emotions: why are they such arseholes? Why do they just have sex and why won't they say they love us, and things like that, we had great discussions, it was fab. [...]

I think I had this little breakdown, I got very depressed when I was about seventeen, I spent six months just hardly talking, just walking around in a daze, and my parents got very worried, and I just had to work through that on my own, and my sister was very helpful, but obviously they didn't know why I was depressed, I didn't even begin to talk about why. But then I started going to the library, mainly because I wanted to be on my own, I just wanted to be free of all this hassle, and realized that there was some gay literature, novels, in the local library, so I read every single one, just like *The Front Runner*, and stuff like that, and then I started realizing that, hold on, this is possible, it's not just like this happens elsewhere, like San Francisco. I realized it could be achievable in the here and now, and after I had sort of realized that, and got some nice positive images to contradict

the stuff in the Daily Mirror, I rang up Birmingham Lesbian and Gay Switchboard and started going to Birmingham, and that was it. [...] I moved in with a fella that I knew, a gay man, moved to Birmingham, which was brilliant, absolutely brilliant, because of the gay scene. I was young, because of the exercising I'd done I had got quite a good physique, I was young and reasonably intelligent, it was a perfect combination, everybody wanted me.

In terms of disability, I thought what I'd been told to think by papers and the rest of the media and society: they can't help it, poor bastards, they are to be pitied, or pitied and supported, but in a very philanthropic way. ..and I was very frightened by disabled people, if I passed someone in a wheelchair, or somebody with an obvious impairment that was visible, across the street, I wouldn't know what to say, because it was like an alien coming toward me, you get very frightened. You don't want to put your foot in it, you don't want to even talk to them, because you're frightened of putting your foot in it, and either upsetting yourself or upsetting them. So disabled people were out there, this minority, and I thought I've got nothing to do with them, I didn't make the links, I didn't think it was about discrimination.

When I came out I instantly made links about race, gender, sexuality, it's about discrimination ... and then I got very disheartened in the lesbian and gay movement straight away, very early on, about the levels of misogyny. I think people thought I was too serious, because even then the gay scene was quite frivolous, the gay male scene, and here was I at eighteen saying 'hold on, why do you call women "fish" that's really not very nice. ..' and couldn't understand where this was coming from at all. ..I thought we were a community, because that was what I had read about in these books, I couldn't understand that the reality was very different. ...

Like for example, I thought wanting a romance was legitimate and political, whereas a lot of other gay men thought having a romance was like selling yourself down a straight river, [...] and I wanted the gay community to fight for all these choices for all of us, that was what it was all about. It was about being able to choose what we want, whereas gay culture seemed to be going down this road of more and more body fascism,

about casual sex, it's about orgies, it's about cruising, it's a not communicating. [...]

In terms of body fascism, I realized there was stuff going on already, you are never going to be perfect, it's never going to work, so even though I wanted to weightlift, I had to do it for me, it had to be about because it felt good and it was healthy, it's not going to get me the perfect boyfriend, and it's not going to make sex great. So I realized that already, but in terms of disabled people, my awareness of these issues didn't really happen until I started working as an HIV worker and doing my degree, in my mid-twenties, and started to make links politically between sexuality and impairment, and realized that it was about discrimination, but there were these issues about people who were potentially terminally ill with AIDS and HIV, at that point links were not being made between generic disabled people's experience and people with HIV, there were very much separate issues, and the politics developed separately in different camps.

So I finished my degree, got this job working as a gay men's worker, doing safer sex stuff, and three months into that job, I started having seizures at home. At work we got a weekend away looking at team building and planning, and halfway through this workshop it's like time stopped, everything stopped. I could still hear things, but it's like my brain had stopped, it was like information was coming in, but I wasn't thinking about it, and I ended up slowly slumping onto my chair dribbling, stuff coming out of my mouth, and that went on for an hour, two hours. ..

It was like, oh my God, I'm going out with this older guy who went out with me because I'm younger than him, intelligent, presumably attractive, and the very basis of his attraction to me had been jeopardized. Which is ironic, because he had diabetes complications, so he would get very ill, and he could be defined as a disabled person, so I was talking to him about it, and he wasn't a very good communicator about emotions, so I did feel jeopardy within my relationship, I felt very insecure, so I started going to the doctors and I thought I'd go and get some pills and it would be all right, and that was when my voyage began about starting to experience discrimination as a disabled person.

First of all it was the medical profession that was my first contact because I wanted to get rid of these seizures, I wanted to learn to drive, my workplace was worrying about whether I could do the job or not. So first of all, basically my consultant ordered all these blood tests, and he said 'Take those to the nurse and she'll take your blood', unbeknown to him because of my HIV work I knew what all these signs and symbols meant, he was doing a platelet count, things like that, so effectively he was going to test me for HIV without having an HIV test. ..so instead of having the blood taken I stormed straight back into his office and tore into him, 'How dare you have me tested for these things, and it's going to go down on my medical records, if you want me to have HIV tests, ask me, what about pre- and post-test counselling. .." so there was all these issues that I already knew about, besides I'd already had an HIV test. He never once asked me about my sex life, did I use safe sex, was it unprotected, which he should have done, he was just making assumptions because I was gay, I was angry about that.

I demanded a second opinion, and they put me on anti-convulsants, and the diagnosis I had was primary generalized epilepsy. I was drinking alcohol, which you aren't supposed to do, I was taking those drugs for a year, and I was just doped out of it, I can't even begin to imagine how I managed to do my work, but I did. I was quite sharp about saying to my employers 'I have an impairment, therefore I am disabled, therefore under equal opportunities policy you cannot get rid of me, simply because you have stereotypes about whether people with epilepsy can do this job or not: I can do this job, I have demonstrated that'.

I already knew the personal was political, not just for gay men, not just for lesbians, but also for women and black people, so everybody had a model that covered this, so it was easily transferable into my experience of impairment. The problem was that I was still surrounded by loads of images and messages that were saying, if you have an impairment, your body is failing you, and any problem you have in life is your body's fault - the medical model -and that's really hard to ditch. And because the drugs weren't working in stopping my seizures, my diagnosis changed, they thought maybe it's psychological, because the seizures didn't show up on the graphs. The thing about diagnosis is fraught with problems, unless you have a clear diagnosis, essentially service providers don't think your

impairment exists, and that's really frightening,. because you're dependent on them for services, or judgements, or pieces of paper, in order to carry on working. I've got plans for a career. ..

What happened was, I went to a UNISON conference, lesbian and gay conference, I went primarily because I was gay. There disabled members' caucus meeting at the conference, so I turned up to it ... I grabbed a disabled guy I knew at coffee and said 'Look, I have seizures, am I disabled?', because you have these stereotypes like, you are only disabled if you are in a wheelchair, or you are blind, or BSL is your first language. I still wasn't sure: 'Am I disabled enough?', basically. That's about a medical model, like society telling you there is such a thing as deserving and undeserving disabled people in order to provide any limited services. There's a hierarchy that someone is operating and you take that on board and you think 'Oh, I'm all right really'. Denial.

I think the biggest thing was talking to other disabled lesbians and gay men, it was just wonderful, and I learned so much. At last I've got this forum where I can talk about what was happening without feeling like losing control, feeling not attractive, all that stuff. I could talk to other disabled lesbians and gay men and be understood. And then what happened was that I bumped into someone with epilepsy who was talking about stuff exactly the way I felt, the whole thing about losing control...

I think the practicalities of the discriminations are different: when I was just gay and not disabled I didn't feel like every day someone had control of my life and was limiting me, as a disabled man I feel that every day of my life. Like tonight I want to go out, have I got enough money to pay for a personal assistant to be there to look after me, because I want to go to a night club? [...] I think I am more at home in straight disabled company than I am in non-disabled gay company, because the gay male scene is so much into body fascism and the body beautiful. I go out in my wheelchair on the gay scene, I've been spat on, I've had a bad time, whereas in straight disabled company my sexuality is more accepted than my being disabled is by gay men. Homophobia is easier to deal with only in the sense that it's much more difficult for people to stop me doing things because of homophobia, physically doing things, like getting a drink from a bar, like turning up to meetings, it's very difficult for them to say 'fuck off', I just

say 'fuck off' back. It turns into a tow, which is like, you have to have the confidence to do that, it's not very nice, but if you've got the confidence it's within your power to challenge, whereas in the lesbian and gay community there are loads of practical problems, obstacles that are put in your way that physically stop you taking part. [. ..] In terms of priorities for change, I think for the lesbian and gay community, it's like 'Let us in, you bastards', the time has come to change the physical structure of the lesbian and gay scene, not only in terms of access, in terms of ramps, lighting, sound, but also in terms of the information that comes out, we need more articles in the lesbian and gay press reiterating that we are entitled to be equal members of this community. I think that's going to be really painful, because that means gay men overhauling their notions of what it is to be gay and what it is to be sexy, and I think that's going to be extremely painful for large numbers of gay men, but I'm not going to rest until they do [...]

I think with the disabled people's movement, it's about welcoming us and our experiences as lesbians and gay men, and our experiences of the politics of sexuality, and acknowledging that we can be really effective leaders within the disabled people's movement. It's not only around liberating us as sexual creatures, but also because of our political experience elsewhere that we are fundamental and central to the movement.