

Chapter Two (in *The Sexual Politics of Disability: Untold Desires*, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 16-48)

## **Two**

### **Barriers to Being Sexual**

#### **Introduction**

The social model of disability, as developed by radical disabled people in the Union of Physically Impaired Against Segregation (UPIAS) in the 1970s, suggests that the problems of disability are caused by society, not by impairment. Rather than blaming the individual, or locating the problem in defective bodies, this approach focuses on social and environmental barriers, cultural prejudice, and public attitudes. The social model is a valuable corrective to the prevailing approach to disability and sexuality, because it encourages us to examine the social processes which make it hard for disabled people to express their sexuality, and the particular difficulties caused by the attitudes of parents and professionals, the inaccessible environment, and the lack of appropriate services.

As well as UPIAS, there was another strand in the early disability movement in Britain, which focused on personal and subjective experiences as well as on the structural oppression. The Liberation Network of People with Disabilities highlighted the emotional cost of experiencing segregation, disempowerment, and prejudice, and tried to explore ways of individual disabled people developing positive attitudes about themselves, rather than the dependency and negativity into which they had been socialized. Again, it is suggested that the distress associated with disability is a result not of impairment itself but of the ways in which people with impairment are treated by society (Sutherland, 1981).

In this chapter, we will combine both approaches to understanding the situation of disabled people in Britain. We hope to explore both the structural barriers and the personal problems which create obstacles to disabled people's emotional and sexual development. We start with

upbringing, then discuss sex education, access, residential care, personal assistance, and finally the whole issue of self-esteem and internalized oppression. It is our view that the emotional states of disabled people are attributable to their social experiences, which is why we explore these experiences first, and conclude with their effects on individuals. We need also to point out that disabled people are actively resisting the barriers which are outlined: as we will show in the final chapter, changes are under way, initiated by disabled people themselves in most cases, and we do not want to suggest that disabled people are defeated or downcast, when the truth is that many disabled people are battling for a better deal.

## **Socialization**

Most people start thinking about sex at a very early age. Initially perhaps to ask where we came from, or how our little brother or sister arrived on the scene. We then pick the thread up some years later, when we ask more questions about our changing bodies and again when our romantic interests begin. However, disabled people are discouraged from engaging in these discussions, or are not provided with answers, as sex is supposedly not something that we need bother ourselves with. As the mother of a disabled young woman stated, on hearing her daughter had a boyfriend, 'I thought your disability meant that you wouldn't be interested in boys, and that your father and I would be saved this embarrassment' .

The disabled women's sexuality research project 'Sexual Health and Equality' (SHE UK, funded by the King's Fund), revealed the limited expectation placed on disabled girls. Many disabled women stated that they grew up in families where they were treated differently from their non-disabled siblings. They were not expected to have sexual feelings, or show any interest in sex as adolescents. One respondent stated that her sexuality was forbidden or crushed just as it was emerging in her mid teens. She is still recovering from the damage done in those early years. Of women in the study 37 per cent stated that their parents and teachers did not expect them, as disabled girls, to form relationships and be partners or mothers when they grew up. This lack of expectation was reinforced as women

found themselves excluded from any media representation: 54 per cent of women stated they had no positive role models.

This lack of expectation from family has apparently influenced these women's self-esteem and confidence about sex. Many women in the SHE study were prepared to talk about their sexual feelings, their success or difficulties in forming sexual relationships etc., but not to each other. Thus disabled women, who could be supporting each other and learning from each other's experiences, apparently find this sharing too difficult. They will talk about sex to counselors or the clergy, even disabled men, but not to other disabled women. It is difficult to unravel the reasoning behind this behaviour. Embarrassment, fear, anxiety, concerns about being non-sexual or too sexual are part of the picture. It would appear that disabled women have no guidelines, no rules of conduct. Nothing to measure one's performance or abilities against. It may be that this is extremely frightening in itself. It would seem that the overriding message to disabled women is that 'sex is not for you': in a desire to understand 'inappropriate' sexual feelings, they seek information and find there is none. The SHE researcher found that there was very little written about disabled women's sexuality, and what was written by non-disabled people, largely medical professionals. Accessing information is a major barrier to many disabled people. The information is either not available or it is in a format which is inaccessible to the particular needs of the individual: for example, tape or Braille is not readily available, and simple English formats for people with learning difficulties are still a largely new concept. It is no surprising that confusion, guilt and silence are the end result.

Ethnic origin and religion influenced disabled women's sexual identity. Many women stated that sex was a taboo subject owing to the religion of the family and community. It would appear that additional oppression makes it harder to break that silence. Black disabled women in the SHE study were pleased that women were addressing this subject; however, unlike their white sisters, they did not want their experiences recorded. They were happy to contribute but they did not want to be identified with that contribution. Thus disabled women are denied the appropriate information about sex and speak out about their sexual experiences.

It would appear that children have more expectations of disabled people than adults. Disabled people have been stressing the importance of integrated education, not only for improved educational standards attained in mainstream schools but because of the positive impact of growing up alongside others who are different. Stuart attended a mainstream school where he was subjected to bullying and the cruel reality of some children. However, he was bright and able to use this to retain a sense of himself. Although the teasing was painful, there were expectations of Stuart becoming a sexually active adult::

'One time some lads were joking on about me, driving a blue three- wheeler car and having children, having spacker [spastic] children. But that was interesting in that they didn't deny that I was sexual and they perceived what they would have as adults, I would also have.'

Thus expectation is important in the development of self-esteem and self-actualization. If disabled children or adolescents receive negative messages about their sexuality from trusted authority figures it is likely that these will be accepted as truth. Disabled children, like their non- disabled peers, need to know that the world has endless opportunities open to them and their destiny is shaped by a combination of personal preference and choice, not by imposed restrictions by frightened care-givers.

## **Segregation**

There is a considerable literature on so-called 'special needs' and 'special education' (Barton, 1987; Fulcher, 1989), and the disability movement has been extremely critical of prevailing policies for education of disabled children. It is suggested that special education is problematic, both because it is often poor-quality schooling directed at therapy, not education, and because it separates disabled from non- disabled children: the former 'grow up isolated and institutionalized, and the latter grow up ignorant and prejudiced about disability. Many disabled people are removed from family, friends, and culture at a very early age to be provided with 'special' education, often as boarders, many miles away from home (French, 1996). They lose contact with local children and important bonds are broken or

never established. Phillipe, a deaf child of hearing parents, describes his experience of being taken to a boarding school for deaf children:

'I left home to go to school at two or three years old. My parents took me off to school, left me there and my father went first, then my mother, they never said goodbye. There were just communication barriers. They had gone and I couldn't understand why. I just thought they weren't interested in me, I felt totally confused, I had to stay there and mix with all these other people. It was really a terrible time.'

Because they often experience damaging isolation, without really knowing why, not surprisingly many disabled children grow up believing that they are the problem. As Kirsten states:

'It is tough growing up different on a south London housing estate. The kids thought I was extremely snotty from a very early age, but I couldn't see them, I didn't know who they were, I couldn't see them and I couldn't explain. Maybe that would have made a difference. Maybe not, but they took the piss anyway. There was no one else on the estate with a disability. Not anyone who would admit to it anyway. So my peers assumed I was rude, snotty, stuck up and generally hideous, and believed it.'

Disabled children miss out on the discussions about sex. They are not involved in swapping stories or magazines about 'the facts of life' with siblings or other local youngsters. As Jeremy explains:

'I used to go through such angst about not having any friends on my estate and seeing old friends going to schools that I could have gone to but I wasn't allowed. They used to see me getting on this bus that came outside the house everyday to take me to my "special" school. They changed and I changed and we grew in different directions and we didn't see each other. They just saw me as the cripple at the end of the road, being bussed off to school. It was quite traumatic.'

The segregation that starts in infancy continues into adulthood, and disabled teenagers find themselves segregated from their non-disabled peers. There may be the occasional opportunity to meet at 'special

organized events, such as PHAB (Physically Handicapped and Able Bodied) clubs, but many disabled people we spoke to have had negative experiences of these clubs. Although they are a so-called integrated environment, the disabled young people were aware that they were in the minority and that they were different. They felt that many young people were with them under sufferance and they were being patronized. Their status as 'different' and 'other' meant that they did not share stories or ideas about sex. Even at this age there was an awareness that sex was somehow not for these disabled youngsters.

Who fancied whom, or what went on at the end-of-term party, or who did or didn't get into the over-eighteens night at the local night club, was of no relevance to them, as they knew they were not part of this life.

Education and socialization are partly about internalizing social values and attitudes. Cultural norms of physical fitness, perfection, and the body beautiful would appear to confirm disabled people's assumptions of inferiority. Jeremy was aware of his impairment and knew he was viewed by the other kids on his estate as the cripple who was bussed off to 'special' school. However, when he went to his local PHAB club he reported being able to patronize those disabled young people who were more impaired than he was. It was many years later, when he began to feel more positive about himself, that he was able to look back and accept that he had seen himself as superior to those 'real' disabled people who were wheelchair users:

'I was still in denial about being disabled and if I saw someone who was disabled, I didn't want to talk to them and if I did, it was as if I was able-bodied doing the old patronizing bit.'

He had felt both sympathy and disgust for other disabled youngsters, but he had not identified as one of them. As he saw it, there was nothing attractive or positive in identifying as a disabled person. Being disabled was a completely negative experience that had taken him away from school friends and local kids and diminished his chances in life. His disability was just something to hide, he would try to pass as non-disabled whenever possible and was pleased that he could do this from time to time.

It would appear that disabled children were able to sort out who was most disabled, or who was least desirable because of their impairment and, on occasions, use this information to their advantage. Charles describes how he exchanged help with maths for sex. Zebedee describes his experience at a school for children with multiple impairments, where the majority of children had limited intellectual abilities and he was considered something of a catch, as he was by far the most intelligent child in the school. He explained:

'Being bright enabled me to avail myself of opportunities which shall we say were not usually available to other children. So I was able to partake in a certain amount of sexual exploration as a teenager.'

Daniel described how a 'pecking order' was established at his 'special' school. Boys had sex with each other regularly, but which boys they had sex with was important, as he explains:

'at the age of eleven, a special school for boys where there was plenty of opportunity for sex and I had a lot of sex there with a lot of different boys. Looking back it was the best thing about boarding school. The most desirable boys were the haemophiliacs because they were closest to being non-disabled, almost god-like. The least desirable were those with muscular dystrophy, and I felt I was somewhere in the middle.'

## **Sex education**

Lack of information can be a major barrier in many areas of disabled people's lives, particularly in relation to sex. Sex education should be a vital part of all young people's schooling. Because of widespread ignorance, misinformation, embarrassment, and peer pressure, it is important for the correct information about the biology of sex to be imparted, but within an overall context which is relevant to modern life. There are legal prohibitions on teaching children about homosexuality ('Section 28'), which are a major obstacle to effective sex education and to egalitarian education in general. Because there are dangers, as well as pleasures, involved in sexual activity -unwanted pregnancy, sexual abuse,

HIV transmission and other sexually transmitted diseases -it is important to convey information openly and effectively.

Disabled people reported a failure to deal with these issues. Teachers parents and centre workers seemed often to place low priority on sex education, or to convey the bare minimum facts, or to protect disabled people from information which was felt to be inappropriate. Clearly there are differences according to whether disabled people attend special school or mainstream school, but the situation in general has historically been a problem, and much of the time is still an issue.

Zebedee is in his late fifties, and went to a special school:

'The situation [of sex education at school] has altered since then, but it was absolutely appalling and when I was at college, I was called in to the headmaster's study just as I was about to leave and he said "I hope you get on very well", and so on, "I look forward to hearing from you", "I hope you get employment", and all the rest of it, I had trained as a shorthand typist. Then he said "Is there anything you would like to ask me?" I said "I don't think so", and that was it, the interview was at an end.

'Now some years later, he came to see me and the matter of sex education came up and it became clear that he thought that was the opportunity when I should have asked him anything I wanted to know about sex. In all honesty, are you ever going to ask a headmaster "How do you bonk with a girl?", when you are on your last day and he calls you into his study and you are wetting yourself with fear, because you think you might be on the carpet for something? It was really crass, but, that was the only sex education that I got as far as the academic world was concerned, and I got all the rest for myself.'

For disabled people now in their twenties and thirties, this *ad hoc* approach continued, as Eddie described:

'I remember when we used to have sex lessons at school, which was this woman and basically they asked your parents was it OK, and then this woman would sit you down in a room on your own and ask you questions:

I was fourteen, and this woman asked me "Do you masturbate?" I didn't have a mother, I had a Nan. I didn't speak to anybody about this sort of stuff and this woman came out with it like that. It was difficult, because you couldn't say no because she might say "My God, you cannot have kids", and if I had been told then that I couldn't have kids I would have topped myself, there are no two ways about it, because it was important *to* me, not the idea of having sex, but I mean my own kids, and that's still with me now, although I wouldn't top myself now. And she had asked me "Do you masturbate?" You would say "yeah" because you were scared of the other kids. I told her I could get erections, I could give sperm. They did sex education, where the man puts his penis into the woman, all the biological stuff, it's all technical and big long words, it was all about how babies are made, we weren't told this is what you will be doing, and all diagrams, all the pictures, but none of disabled people.'

For Eddie, the basic information which was conveyed increased his anxiety about sexual performance:

'The pictures they showed us, these diagrams, these guys were hung, I though I'm not that good ... but that was the other thing of course, penis size, the idea that when you masturbate it grows ... but mine didn't grow enough. I thought about sending away for these extensions. I think it's more than the usual worries guys have about penis size, to some extent it can be worse, because of the proportions of our bodies or because of sitting down all the time, whatever, the shape of the penis. I think we tend to worry more about the idea of whether or not you can *use* it, and also the pressures put on you by family, the pressure I am under, although perhaps not even meant, because of whether or not I am going to be able to use this thing.'

'My sex education at school was extremely basic, just confined to the basic sexual act. We were led to believe sex was dirty, frightening and not to be discussed, and only indulged in if you were married and wanted to have children. Until I was in my twenties and thirties I knew almost nothing about contraception and/or safer sex.'

'I interviewed some young adults who were physically disabled and was shocked to find that two had been withdrawn from sex education lessons

and the others had no recollection of any such experience in their special schools. I was told about a hysterectomy which had been performed without the informed consent of the interviewee, unwanted parental intervention in relationships, lack of opportunity and lack of knowledge about how to manage physical situations.

'Much was made of boyfriends, but in a way which I found patronizing and condescending. It seemed to focus on friendship which had no potential for any sexual development. The young people were not seen as having sexual emotions or desires.'

*TS: Do you think people try to protect you too much?*

All: Yes. ..parents " ..

Paul: They say be careful, what time are you going to be back? .

*TS: That sounds like how you might talk to a child ... how does it make you feel?*

Paul: I say, I am all right, I can look after myself.

Andy: When I was at school, a sex education film was shown, and my mum thought I was not old enough at that particular time to watch it ...Then something came up at the day centre, and I was older then. .. (laughter) This worker at the day centre was giving a talk, and she was holding up a condom, and the manager of the day centre came in, and her face was just beetroot.

*TS: How old were you at school when your mother wouldn't let you see the film?*

Andy: About thirteen or fourteen.

*TS: And at the centre?*

Andy: About nineteen.

People with learning difficulties face some of the biggest restrictions in terms of availability of sex education. Whereas in other areas of life the trend is towards 'normalization', in other words, fitting people with learning difficulties into the roles and values of the rest of society (Wolfensburger, 1972), this does not seem to prevail in the area of sexuality. Sometimes basic biological facts are communicated: only rarely are social aspects fully explored. Hilary Brown (1994) has discussed this problem, and suggests

that services have an implicit role in regulation of sexuality and creation of sexual boundaries (1994: 124):

Is there an unwillingness or inability on the part of services to create opportunities for sexual relationships or support people in sexual partnerships? Why have we not seen the emergence of sexuality 'coaches', relationship finding agencies or marriage brokerage? We know such rigorous strategies can work in other areas of people's lives so why have they not been adopted to open up real sexual options?

Brown argues that this lack of effective work stems from prejudicial attitudes: 'Fears and myths about sexuality have been projected onto people with learning disabilities, they are framed as asexual, or oversexed, innocents or perverts' (Brown, 1994: 125). Moreover, people have often been infantilized, as is shown by the workers' use of terms such as 'boys and girls', or dehumanized, as indicated by terms such as 'males and females'.

Brown concludes' that the concept of normalization sounds good, but in practice hasn't prioritized sex: 'What is valued for others is greeted with fear, hostility and disapproval by members of the public when it is people with learning disabilities who want to engage in sexual activities' (1994: 128). Moreover, there is no such thing as 'normal' sexuality: normalization often means assuming that people with learning difficulties all aspire to heterosexual, familial relationships. Finally, sex for people with learning difficulties is not a right normally granted, but can only be achieved by challenging 'normal' expectations (Brown, 1994, 141):

People with learning disabilities who do assert their right to what is perceived as an ordinary sexual life are actually breaking the rules for their 'kind', and should be supported in what is an act of rebellion rather than conformity. Currently services accommodate such acts by burdening heterosexual relationships with controlling romantic overtones in a last ditch effort to desexualise them. Meanwhile men and women with learning disabilities who choose

gay or lesbian relationships are not supported in turning their preference into a coherent and explicit sexual identity.

One of our disabled respondents, Sue, had worked in a school for people with learning difficulties, and her account illustrates some of Brown's arguments:

'I mean if they were talking about sex education it's quite basic, I don't think there is any information about contraception. ..the school I was working in, the information about contraception, and what it meant to be having a loving sexual relationship, there was none of that at all, and yet there was lots of sexual feelings flying around that school. [ ...] We used to go away a lot at the weekends, mixed male and female, and also non-disabled young people, and disabled young people, sixteen and seventeen. Sexual activity was very much prevalent, especially when a lot of their peers of the non-disabled group were together and they just had sex, because it was coming up.

'One young woman who had Down Syndrome, and had a boyfriend who had Down Syndrome, they had been boyfriend and girlfriend almost since about ten years old, out of a special school they had been to, and it was all very cute and everybody used to smile, thought it was great, we used to talk about it in the staff room, this is lovely, L and B, but that was it, it was always how cute it was. And she came out one evening, just said "B wants to touch me in such and such a place", and she said "He keeps wanting to touch me on my left breast". I said "Well, do you like it?" and she said "Yes, I do", and that's what she was so upset about, because she liked it but had been told all along that it was wrong to let anybody touch you there, and having any sort of sexual feelings was bad and dirty. There was just no information at all about what that meant, and what those feelings were, that it was all right to have those feelings, and if her and B wanted to explore that more, then it was all right, I it could be done in a safe and private environment. The attitude was that she needed protecting from that big bad world out there, that she could be abused by everybody left, right and centre, that she was a very vulnerable person, because, although she was a woman, she had a mental IQ of a very young child, and therefore needed

protecting. And their way of dealing with it was to tell her it was bad, and then she was left with all these frustrating feelings.

'We went to a family planning centre, and they gave us a training session for us as youth workers about inter-personal relationships and sexuality for young people with learning disabilities, and it actually was very, very, good. We had to sort of go and look for training and it was based on something from America, and it was only around learning disabilities, I am sure that issue is going on all over the place. Again, as I said, that young woman was put on the pill, we were on a narrow boat, she was taking these pills, she didn't know what it was, why she was taking it or what it did, no one had explained to her and she was nineteen years old and no-one had bothered telling her.'

Maura Banim and Alison Guy have been working on a research project which is an example of appropriate sexual health work with young disabled people, based on peer education. They suggest that there are conflicting messages: on the one hand, adolescence is about risk taking and sexual activity, but, on the other hand, disability is about tragedy and passivity. Participants in their research had very limited experiences of sex education. Families were seen as having predominantly negative perceptions of their sexual health needs. Neither could these young disabled people discuss the topic with their key workers. Consequently, there were major difficulties in accessing information. When asked who they thought would be good people to help disabled people learn about sex, other disabled people came top of the list (Banim and Guy, 1995).

We have been discussing what Banim and Guy refer to as the 'discourse of prohibition and risk' around sexual health, and certainly the ignorance and over-protection we have highlighted are sure to have a negative impact on sexual identity and sexual expression. If many disabled people are not given access to information, then later emotional and sexual development may be restricted. Furthermore, lack of appropriate education may put people at risk: in the area of safer sex, as well as with the broader issue of contraception, lack of information and education can have disastrous consequences for disabled people. For example, Graeme Greig (1995) has performed some research into health authority HIV/AIDS services for

people with visual impairment and found very limited provision, and indeed very little awareness of the issues. Many services responded that they prioritized gay men, but obviously did not consider that gay men could have visual impairment. Neither did they prioritize working with people with AIDS who become blind as a result of associated illnesses. Agencies seemed to be assuming a homogeneous population, and that the absence of requests indicated an absence of need for services, both assumptions being clearly inaccurate. This situation is duplicated in general for disabled people who are segregated, and there are particular problems for people who have communication issues. For example, lack of accessible HIV-related information contributes to a disproportionately high level of HIV transmission amongst the deaf population.

Progression of sexual development to that first (sometimes planned) sexual encounter means more hurdles for disabled people to overcome. Family planning services are usually inaccessible to most disabled women and men. If the premises are accessible, the attitudes of staff members are usually so oppressive that the service remains inaccessible to disabled people. One young woman described her persistent attempts to obtain the pill. So many family planning clinics were just not wheelchair-accessible. When she did eventually see a 'friendly' GP, he insisted on offering 'genetic counselling' even though her impairment was not genetic and she had come to prevent a pregnancy. Sadly many disabled people would not be as persistent as this young woman and could either give up on sex, or engage in unprotected sex, risking health and unplanned pregnancy.

Many family planning services are unaccustomed to dealing with disabled women and make do attempt to provide a more inclusive environment. When disabled people seek help, it is often not available or inappropriate. The limited number of initiatives taken have been almost exclusively for people with learning difficulties and are commonly a knee-jerk reaction to their sexual expression. The Family Planning Association have a community-based project for people with physical disabilities in Northern Ireland run by a disabled woman. However, much of what they! do is in response to people with learning difficulties living in the community with fewer restrictions and inevitably becoming sexual. they work with parents, carers and professionals 'coping' with and 'coming to terms' with the sexual

activity of their charges. Sex education is about removing the problematic approach to the sexuality of P40ple with learning difficulties. However, little progress has taken place in the area of physical or sensory disability.

The Brook Advisory Centres have a policy of never turning anyone away, but as many centres are not accessible this is sometimes inevitable. The service can be taken to the disabled person but this approach returns disabled people to the 'special' services arena. They have minicomms (text telephones) for people with hearing impairments; however, work with young disabled people is not prioritized and therefore funded to the minimum. As with the FPA, more work is being done with people with learning difficulties: other disabled people are referred to SPOD (Sexual Problems of the Disabled). SPOD unfortunately receives very few direct contacts from disabled people, so it would appear that disabled people are going without an essential service.

### **Physical barriers**

A major cause of the oppression experienced by disabled people is the inaccessible environment of modern Britain. All the facilities which are taken for granted by non-disabled people are likely to present barriers to disabled people, including housing, employment, transport, and leisure facilities. This is a direct cause of the segregation and isolation of disabled people. It is harder to, get jobs, harder to meet people, harder to live in the community. Not only does this affect disabled people's educational opportunities and income potential, it also restricts their social life, and particularly their opportunities to find partners. The SCOPE report referred to earlier, *Disabled in Britain*, found that many of the 1,568 disabled people surveyed felt oppressed. Half of them often experienced people staring at them in public, many experienced name-calling. Half the sample did not have as active a social life as they would have like, and this was the issue which people were most concerned about, coming before lack of money. The proportion of people living alone was twice the national average (Lamb and Layzell, 1994).

Colin Barnes's study, *Disabled People in Britain and Discrimination* (Barnes, 1991), outlines the ways that disabled people face barriers in all areas of life. He shows that it is not just physical access which causes problems, but also social and economic factors which render disabled people disadvantaged. While disabled people obviously experience negative attitudes on occasion, the problem is more deep-seated and structural than just individual education, and this is the reason why the disability movement has campaigned for comprehensive anti-discrimination legislation.

Readers are referred to Barnes's work if they wish to get a full picture of the extent of physical and social discrimination, which is outside the scope of the present study. Our respondents did, however, stress the ways in which barriers restricted their lives. Paula told us:

‘Some of the places I used to go when I was still struggling around with a stick or crutches, I just don't go to anymore. I have tried to, one restaurant that I used to go to complained because I called in one lunch time when I was in town and they said “Where have you been?” I said “Make it fully accessible and you might see me again!” I thought, when are people going to take the hint that it's financially a good idea to make public buildings, especially pubs and restaurants, fully accessible?’ If you want my money, make sure I can get to the loo. Thanks!’

Disabled people like Paula are restricted in their choices:

‘It usually means that the places that I go to, if I have to make a huge effort to get in I just won't go, I'll go to places where I feel comfortable, where I feel I don't have to struggle – where nobody's watching me trying to get into an accessible loo – and so I generally go to places that are amenable to me. I am very selective these days’.

Alternatively, disabled people have to cope physically with the barriers presented by unadapted environments, as Sara told us:

'I've dragged myself along floors to loos, pulled myself up stairs on my bum, lifting my legs, step, by step, I've pulled my arm muscles doing this and injured my sacrum as well as worsening pressure sores.'

Sara had had to move to accessible accommodation after she developed her impairment, and this also had the effect of isolating her:

'I have joined some women's groups to meet people, but I am isolated and alone a lot. Before, I lived in big houses of lesbians, so people were always around. Due to my disability I needed a specially equipped flat, so I've had to stop living with others and get a place of my own, so I can get around. I miss the company of people around and it's the first time I've ever lived alone. It is still strange, but I'm getting used to it. Becoming disabled changed my whole life, how I lived, I had to give up work. Many places I went are now inaccessible and so my friends can't invite me out because they know won't be able to use the toilet, get up stairs, etc. They do make an effort to go to accessible places sometimes, but find them boring because everyone's somewhere else that we know, somewhere I can't get in easily.'

We know that discrimination in employment exists: a disabled person is much more likely to be unemployed than an equally skilled non-disabled person, and most disabled people are not in paid employment, and those who are employed are paid less. The reasons for our unemployment are seen as hostile environments, lack of opportunity to gain appropriate skills and the negative attitudes of employers. This anecdote from Louise highlights several of these points:

'The other thing is recently having had an experience of feeling less than human by having a disability, which is not something I've normally felt. I was really shocked by that, I was really shocked by the impact it had on me. It was a time when I was waiting to be interviewed and I had to climb stairs to get to the interview, and then I was told I had to climb more stairs, and some people I said "Would you like us to come down and have your interview down here?", and I felt really like I'd been patted on the head, it was dreadful because then I had to immediately to into this panel interview

and I had to really try to stop myself from crying. It was difficult, I found it really difficult’.

Work offers several important benefits, including cash to afford social outings and a group of people, who are potential friends or lovers. It also provides the disabled person with a sense of worth and self-esteem which is invaluable, if one is going to enter into a mature, equal and health sexual relationship.

Apart from the obvious physical barriers to disabled people gaining access into pubs and clubs, where they might meet potential partners, there are also the difficulties imposed by the negative attitudes of personnel working in these establishments. Many have been refused entry to restaurants as they might ‘put regular customers off their food’. Others have been turned away from clubs because they are considered ‘unsightly’ and will negatively affect the atmosphere and image of the club, or classically, might present a fire hazard. Dafydd describes his experiences:

‘Going into a crowd night club, people trip over you, they are pissed, they are cruising, you get this look that basically lets you know you’re not welcome. It’s like “you are reminding us of something unsexy, get out of the way”’.

Even social events or venues specifically for ‘minority’ communities will refuse disabled gay or disabled black people admission.

For those who make it past the door there are particular problems connected to particular impairments. Blind or visually impaired people have described the difficulties of either initiating an advance or being able to respond to a ‘come on’ when eye contact and visual clues are not possible. As Kirsten describes, ‘I cannot make eye contact and respond visually to body language. I am often thought to be rude, drunk or not interested.’ Neil said:

‘At parties sometimes, it’s not been unknown for me to just sit there for about half an hour or even longer before I get talking to someone, and that’s not a lack of confidence on my part, it’s the fact that there could be

dozens if not hundreds of people in any one room, and to start wandering round you are not going to bang into people, you are going to knock things over, etc., so it's partly you just want to attract that attention, undue attention to yourself.'

It is necessary to develop different adaptive strategies to deal with particular impairments. However, non-disabled people find it difficult to comprehend how disabled people manage, as Neil also told us:

'The night Sue and I got together we had gone out to a friend's house to dinner. My friend said things like "Isn't there problems around getting into relationships if you're a blind person? Because I couldn't see, how would I be able to .make eye contact. .. " issues of physical attractiveness and that sort of thing: "How would you actually find your partner? ...How would you actually take part in sexual intercourse if it came to that?" and what have you. Some people have said, it takes place in the dark anyway.'

Communication is an obvious problem for disabled people. It may be a case of actual difficulties with speech or hearing that inhibit communication or it may be that spoken English is not the person's first language. People who are born deaf are most likely to use British Sign Language (BSL) as their first language, yet BSL is not taught as a 'minority' language and BSL interpreters have to be booked weeks in advance: not much room for spontaneity. Thus trying to negotiate one's way through the hearing world is fraught with difficulty, comparable to the obstacles faced by other minority communities in British society.

Some of the barriers experienced by disabled people are direct consequences of their impairment -for example, lack of eye contact. Others are caused by disabling factors such as lack of access or understanding. Both forms of restriction can be alleviated, circumvented, or removed with appropriate provision and behaviour on the part of society. Unfortunately, the experience of our respondents is that this is often not forthcoming.

## **Residential institutions**

The inaccessibility of the public environment, the lack of accessible housing, and the economic marginalization of disabled people are the main reasons why disabled people have been historically segregated into residential institutions. While policies are changing -and we will discuss aspects of community living below -many disabled people are still incarcerated. This can potentially have two negative effects in terms of sexual rights. First, because disabled people are often infantilized in an institutional setting, it is rare for people to be permitted to express themselves sexually. Second, there is a high vulnerability to physical and sexual abuse. We will discuss this aspect in the later chapter on 'bad sex'. Ironically, the risk of abuse is often cited as a reason not to allow disabled people to learn about sexuality or form relationships, though it is often the case that sexually active residents would cause difficulties for those who run the institutions, or would challenge the assumptions about disability which dominate such settings.

Traditionally, charities resisted sexual relationships. Glynn Vernon (1995:22) quotes two former residents of Combe Farm, a Spastic Society residential centre:

In those days, the Spastics Society could not cope with the idea that disabled couples had the same needs and desires as everyone else. Marriage was out of the question. We were allowed to get engaged, but that was all ... The men slept in their dormitories and the women in theirs. Any sexual activity just wasn't allowed.

Nigel's account indicates that these restrictions are still maintained in some settings:

'People with learning difficulties are treated badly. I know of day centres and residences where sex is banned. This is where people live and they can't have sex. Sometimes day centres are the only places where people can socialize and sex is part of that, although people need to be discreet or it needs to be appropriate, but to ban it is wrong. I know of two gay men

who were forming a relationship and the staff separated them so that they could no longer be together. All this needs to change.'

Now, shifts towards community care plus more enlightened attitudes may open up more possibilities for relationships. SCOPE, formerly the Spastics Society, now has a policy stating that 'everyone has a right to have opportunities to love and be loved and to be helped to achieve relationships that are fulfilling'. In 1995 the John Grooms Association for the Disabled, another charity running residential institutions, also started the process of developing a sexuality policy. But these changes are slow in coming, and it will take longer for policy decisions to feed through into practice. Many agencies and workers believe it is their role to protect 'innocent' disabled people from sex, notwithstanding the fact that residential institutions have always had a higher incidence of sexual abuse. Disabled people's rights to sexual expression, on the one hand, and to freedom from sexual abuse, on the other hand, are not assured in the majority of residential settings.

### **Personal assistance**

An important part of the liberation of disabled people has been their insistence on the right to live independently in the community. Centres for Independent/Integrated Living (CILs) have been established by disabled people. These are Centres of excellence, controlled by disabled people, where information, advice, and practical assistance can be obtained, in order to enable the disabled person to go through the process of moving from the family home or out of residential care and into their own home, with the care they need in order to maintain independence. The important difference about this movement is that it is about self-determination of the disabled person who is in absolute control over their destiny. Once the nuts and bolts of independent living have been established -i.e., the money found, the accommodation and personal assistants (PAs) in place -decisions about daily living have to be made, and it is the disabled person whose life is facilitated that has to be in total control of that assistance.

However, the mechanics of personal assistance may be simpler than the emotional and practical! aspects. Retaining control, and managing the

caring relationship, may take considerable resources, as Kate Cooney (1991) has argued in *The Guardian*:

No, it's not easy being 'cared for'. It's not just the messy bits. It's no longer being able to nick a chocolate biscuit out of the fridge, or experiment with make-up, or grab just the right scarf to set off your jumper as you rush out of the door. Always, always, you have to ask. These things may seem insignificant nit-pickings compared with the more obvious dramatic changes wrought by disability, but taken together they are as momentous as the arrival of the wheelchair or the loss of your job. As they are given up, a little bit of what outwardly makes you an individual is eroded. Your carer has to run parts of your body for you. If you insist it is run exactly the way you would have run it, you will be ridiculously demanding. but it still hurts to let go.

Inappropriate carers may create additional problems, as Stuart outlined to us:

'In terms of personal care functions, which are quite personal, you need personal assistants who are sensitive and don't try to dominate you. You basically don't need people who need to be carers. When I first got funding for a personal assistant, I got one from an agency and it was a constant battle of routines. For example: getting dressed, it was like, I would give him instructions to put my boots on in a certain way, and my socks in a certain way, but he would negate that by doing it his way. He felt that was his decision, and I had no choice at that time because I wanted to employ a male PA. I had no choice until I found other people, but I had to put with that'.

Because the PA performs intimate tasks, and has a key role in the disabled person's life, it can cause difficulties in relationships, which are no longer a matter of two partners, but also involve a third party. Sian Vasey has written (1995:86):

The problem for me is centred on relationships and particularly how you have a sexual relationship when you need help getting to

bed, turning over in bed, someone to come into the bedroom in the morning to get you up, and so on. Before one even starts thinking about the problems of intimacy, the issue of more everyday privacy can be a problem. A lot of partners and potential partners just do not like the constant intrusion of the third party and can drift away. My experience is that it can be awkward and embarrassing having a personal assistant present even in quite innocuous situations.

The following account is from Ruth, who is concerned about managing this situation and other aspects of the PA relationship:

‘There is the practicality in terms of privacy. I think I would be much more worried about the reaction of my agency workers because they come and go, they may come in at 7.30 in the morning and find me in bed with someone, I mean at some point that is going to happen and I am just going to have to deal with it. [...]

‘I think also sometimes you can find yourself in an awkward triangle situation, and if they are young women who are not terribly sorted out on the issue it could be a problem, but I kind of feel I will face that when I come to it, but it’s something I would want to discuss with someone that I was having a relationship with [...] I think it is very different to them being faced with me as a theoretical lesbian, to finding me in bed with someone. I am not at the stage now when I need help with the sexual stuff, but that could be difficult, I am not really sure how I would deal with it. [...]

I think a lot of it is going to depend on the reaction of the person concerned, whoever I am having a relationship with. It does worry me, especially in terms of the privacy and also in terms of the quite awkward dynamic, if you were in, a relationship with someone and it certainly was an issue with them, is what you expect the PA to do and whether you expect your lover to do something particularly because they are there and actually it is sometimes easier to get the PA out of the way so you have a bit of space with your lover, and then they end up doing things that the PA should be doing and if they are not used to PAs, which they probably won't

be unless they are disabled and got a PA themselves, in which case we have got a foursome and it gets even more complicated. '

It is not uncommon for disabled people to organize personal assistance in the workplace or to get them to and from a social event. However, assistance that goes beyond the mundane, such as assistance with sexual activity, has to be negotiated without ground rules or guidance. Many disabled people who want to employ personal assistants who will facilitate their sexual needs find themselves with no one to turn to for advice. Individuals must carefully tread this path, often with a sense of frustration and dread or fear of rejection. It is not surprising that many disabled people live with desires and unmet needs for fear of losing essential care. There have been conferences about setting up independent living schemes, including discussion on how to become a competent employer, organize tax and National Insurance, etc. However, this seems to be where the discussion ends. Zebedee's view is that

‘The disability movement needs to get its act together about this issue. If an able-bodied person wants to masturbate they do it. In my view, it ought to be taken on by carers if you can’t do it yourself’.

Many disabled people require assistance to get into particular in order to facilitate sexual activity. However, they may well experience resistance, or outright refusal to help, from carers who believe disabled people should not be sexual. This is a very delicate situation fraught with potential difficulties and one that the disabled person is not going to engage in lightly. However, to take the plunge and summon all one’s courage to ask for help only to be refused is a risk that may well not be taken again. This outright denial of disabled people’s right to be sexual is unacceptable, and agencies that provide personal assistance have a responsibility to ensure that assistance is exactly that, assistance, and that no judgements are made about the nature of the assistance required.

Facilitated sex for all disabled people is still controversial. Many disabled people believe it is about time that agencies that provide care staff have an equal opportunities policy agreed and signed by care staff. This policy should state that they are prepared to work with all disabled people without

discrimination on the ground of sexuality, race, etc. This would at least invite the idea that there are sexually active disabled people living in the community and in residential settings and they may well find themselves working with someone who requires assistance with sex. This issue could provide the material for a prolonged debate about the employment rights or the moral or emotional rights of personal assistants or carers. However, at some stage a decision has to be made about what care is acceptable and it must be the disabled person's right to make that decision.

Another issue is presented by situations in which disabled people form relationships with their personal assistants. This is no an uncommon practice, as a subsequent personal account by Juniper indicates. The second wife of Professor Stephen Hawking, for example, had previously been his nurse/personal assistant. However, relationships with personal assistants cause potential boundary problems, and some politicized disabled people feel it is inappropriate, as Stuart argues:

'I think personally as a disabled man, I don't like what I see when disabled men exploit female personal assistants, first because of the gender oppression which is reinforced, but also lots of disabled men employ sexual pressure upon their personal assistant to have relationships. I just think that it is not on, because for two reasons, one the rights of the personal assistant but also the rights of disabled people. When you look at people with learning difficulties, women with learning difficulties for example are abused by males that work with them, because the workers see it as acceptable to have sexual relationships with them and I think it is incumbent on any disabled man who is also a disabled activist and is aware of social model theory, not to reinforce this acceptance, not to make it acceptable for people working with disabled people to give sex or form relationships with their clients. If it comes to the point where you are attracted and it will happen, then you should then shift that from being a work" relationship.'

Unfortunately the majority of disabled people do not have care packages and personal assistance employed to assist with their requirements of daily living. Many remain in institutional settings or rely on family. For those who are married, the spouse often becomes the carer practically as well as

emotionally. Stuart highlights some of the differences between having a paid personal assistant and having a carer who is a family member or friend:

‘A carer is essentially someone who has an emotional tie, and a personal assistant is someone you instruct, there are no emotional ties, it is a work, employer/employee relationship. You still have to be sensitive to your personal assistant's needs, but with a carer they have much more rights to say "I don't like this". I don't honestly think that family or friends can be personal assistants because I firmly believe there is too much emotional tie and you are heading for real trouble if you try to treat families as personal assistants, because personal assistance often involves giving out instructions -in one maybe two- or three-hour session you could give out dozens of instructions -since you have to be very sharp in giving out instructions and you cannot do that to your family or friend, you have to go with their pace. An example, a friend helped me on a course once and I had to allow him an hour each morning to get ready because he took real care.’

Another difference is that partner or family member who is a carer is not able to resign their post, in the same way as a personal assistant. Caring relationships of this kind can present a range of difficulties. The strain on carer and cared-for can sometimes be so great that physical or emotional abuse to either party may result. Beth describes the emotional turmoil and conflict of being cared for by her husband, who is having an affair:

‘I have always been my own person, and without the MS I would start again. I would seek to meet my emotional and sexual needs elsewhere. Now I feel unable to do this. At the same time I cannot describe how awful it feels to have to allow a man who insists that he loves, and must see, another woman, to put me to bed, turn me over at night, get me up in the morning, or carry out any of the other tasks that are essential.’

Jenny Morris's excellent account of personal assistance and independent living, *Independent Lives*, discusses some of the difficulties when romantic and care relationships are combined (1993:74):

Being helped to wash, dress, go to the toilet and so on, obviously involves close physical contact between two people but it does not necessarily result in intimacy. It is the love between two people which makes the 'caring' relationship an intimate one. This kind of relationship can be very special and some people feel that the provision of personal assistance enhances a relationship, whether it be with a partner, family member or friend. However, receiving assistance within a personal relationship can also stifle independence and lead to an emotionally damaging and physically dangerous situation.

We would refer readers to her book for a full discussion of these issues, which are also discussed in Gillian Parker's *With This Body* (1993).

### **Internalized oppression**

Disabled people suffer from the damaging effects of discrimination and exclusion, resulting from the environmental, attitudinal and institutional barriers described by the social model of disability. However, it is important to widen the discussion further, to address the damaging emotional and psychological barriers that prevent disabled people from becoming fully functioning human beings, with health sexual identities and active, life-enhancing sex lives: these include certain attitudes and assumptions held by oppressed people that create a situation of self-denial or self-harm. These attitudes and resulting actions have been referred to as 'internalized oppression'.

This internalized oppression has been illustrated many times in interviews with disabled people, as Daniel states:

'I know if I met Mr Right, this gorgeous, perfect person I have been waiting for, that nothing would happen, I would be too frightened to allow it to happen.'

He goes on to say that this! may be the reaction also of many non- disabled people,

'but there is something about my distress about my impairment, which although it is so much less now, still holds me back'.

It is usually assumed by non-disabled people that disabled people's distress results from the fact that they have impairments, which are painful or limiting. This is sometimes the case, as Beth states:

'There are many good things in my life, however, my disabilities have reduced the choices I can make, have turned me from being a woman to being a patient with MS, and have altered my sexuality and sexual relationships.'

However, it would appear that our distress is more commonly a direct result of non-disabled peoples reaction to impairment, as Dafydd says:

'My impairment itself doesn't restrict my sexual activity, what restricts my sex life now is other people's perceptions about my impairment, very definitely!'

Psychological insecurity and distress are a result, therefore, of the social relations of disability, not the physical experience of impairment, as Finkelstein argues (Finkelstein, 1993).

An additional difficulty when discussing the taboo subject of disability and sex is that disabled people have not yet developed the language to engage in the dialogue. The movement readily talks about physical exclusion from places of work or leisure; however, it has not yet talked about the ongoing consequences of that exclusion. How do disabled people feel about such systematic rejection? What do people do with their feelings of hurt and disappointment? What defence mechanisms are used to prevent annihilation and what does the realization that one is perceived as second-class, second-rate, and unwanted do to one's ongoing development from child to adult? Patrick describes how he tried to fit in by trying to hide his disability as a child:

'I was the only disabled person in an integrated school. I tried to prove myself by being just as good or better than the others. So I lived through

study and passing exams and getting to university and doing well there too. So in a way I was trying to hide or compensate for my disability. It is only in the last two or three years that I have come to learn to accept it, that it is part of me. That it is silly and stupid trying to hide it and that I don't want to any more.'

As a movement we reflect societal values and find some impairments more acceptable than others. Those with mental distress and learning disabilities are still marginalized within our ranks. Nigel, a gay man with a learning difficulty, explains:

'I feel more comfortable with disabled people than within the gay community. Although I belong to both communities I don't really fit in either. I feel I can't moan about anything, if I want to be accepted. We get such mixed messages, as people with learning difficulties we are meant to be meek and mild and childlike but as men we are supposed to be masterful or angry but when men with learning difficulties take on those attributes, we are seen as monsters. My first loyalty is to other people with learning difficulties because we are not wanted or included. I was sixteen before my father accepted I had a learning difficulty.'

Naoisa, a mental health system survivor, says:

'The disability movement is still coming to terms with people with mental distress within its ranks. Like the rest of society, some disabled people fear us and would sooner we were not around. Then there are those who understand the politics but because we look "normal" they treat us like personal assistants. Just because you can't see my pain doesn't mean I'm pain-free and coping.'

Disabled people are still only just starting to discuss the psychological impact of the discrimination and prejudice, despite an awareness of the problem since the early days of the Liberation Network. Dealing with anger, self-loathing and daily experiences of rejection and humiliation are among the hardest aspects of being a disabled person. Lois Keith discusses these encounters, and strategies for dealing with them (Keith, 1996), but more understanding is needed. Because disabled people experience

negativity, they sometimes also project negativity, which means that disability organizations are often driven with competition, dispute, and distress. Acknowledging these internal issues is a necessary step to overcoming them in the future.

## **Conclusion**

There are many barriers, some which stem from impairment and many more which stem from society, to disabled people developing healthy sexual identities and living fulfilling lives. However, disabled people are equally astonishing in their resourcefulness in overcoming many of these obstacles. As Ann states,

'I'm a different. person now than I was six years ago (following her injury). I had my outbursts but now I live life to the full. I have my own flat and I go out to clubs, pubs, or whatever. ..I'm doing OK, but of course a sense of humour is essential to survival as a disabled person.'

Whilst we should be mindful of avoiding such stereotyping as 'the plucky individual' or 'super cripp' of so many popular misrepresentations (Barnes, 1992), it is important to recognize the gains made. However, society needs to change further, to recognise the many ways that those perceived as different are excluded, and to acknowledge that disabled people are fully sexual human beings, with hopes and desires and the right to fulfil them.

## Juniper

One of my first sexual experiences occurred when I was masturbated by G. I was nineteen and I was living in Essex at a college for the disabled. G was one of the carers. G was overtly very masculine, pipe-smoking, beer-drinking, apparently very rooted in a strong male identity. He had a very powerful personality, dominant, sometimes domineering. He was very good at getting the disabled male residents to rely on him and trust him and depend on him. This certainly wasn't all some complicated ruse. He genuinely cared for us and took a lively interest in our problems. G believed disabled people were always in need of advice and guidance. We were incapable of taking control of our own lives. G had himself become quite institutionalized, having worked in residential homes for over twenty years.

For his sexual advances, G generally targeted the younger, more sexually inexperienced, more emotionally naive of us students. Over the years, G had obviously honed his technique to the point of perfection. When he was bathing you, he would spend slightly longer than normal on washing your penis. Sometimes obviously you get a bit of an erection. G was watching your reactions all the time, carefully gauging your response. When he did this to me, I felt really confused. There was excitement and sexual arousal, wondering how far G would go. At the same time, there was a lot of doubt and fear and anxiety. G would play on these feelings of confusion by keeping up a non-stop stream of salacious talk.

This softening-up process went on for a few weeks. Then, one summer evening, after my bath, G was drying me on the bed. I got a bit of a hard-on. G immediately began to dry my penis very vigorously. Pretty soon, I found myself coming into one of the clinically white college towels. Afterwards. ..feelings of sordidity ...it had all been so strangely cold and unemotional. It happened to me a couple of times. [ ...]

I have opened my article with the case of G, because it reveals so starkly the vulnerability of the disabled male. We so often find ourselves in situations where we are exposed and naked and vulnerable. This leaves us open to domination, and even abuse. Our general existential situation is

quite different from that of the non-disabled male, and has some similarities with the vulnerability of women. I have often reflected on the paradox of being a disabled man. On the emotional and intellectual level, I have possessed, and no doubt to some extent still possess, the basic tendencies I of the non-disabled male: the arrogance, the self-assurance, the desire to dominate and control women. But on a physical level, I am as helpless, as a small child. When I take a bath, I am undressed, then bathed by another person. When I go to the loo, my pants are pulled down by another person. If I have a shit, my bum has to be wiped. When I eat, I am fed generally by another person.

At the time of the enquiry at the college, when everybody was trying to piece together what had happened, I was often asked: 'Why didn't you just say no to G when he was touching you up? Why didn't you protest? Why didn't you scream out?' In this kind of sexual happening, things are rarely so clear: cut. It wasn't a simple yes/no situation. I wanted it, and didn't want it. In our early sexual explorations, we are often lured by that which we perceive to be forbidden. Under patriarchy, every sexual act contains a power relation. In this particular sexual act, all the power lay with G. He was in his forties and knew what he wanted. I was nineteen, and didn't. To him, this sort of thing was a matter of daily routine: when I complained to the principal, a lot of people came forward to give evidence against him, leading to his dismissal. To me, it was new and dangerous and uncertain.

I was lying in a bath, completely naked. G was standing over me, fully clothed. Feelings of vulnerability can in themselves be quite a turn-on: total exposure, the total abandonment of control. All human beings have certain masochistic tendencies. In my own case, I have found these tendencies have often been intensified by the experience of physical weakness and vulnerability. A few days after I had complained to the principal, G stormed into my room. He was coldly angry and subjected me to a torrent of verbal abuse. I didn't know how to react. I was scared. Bizarre as it might seem, the fear gave me an erection, which of course G immediately noticed. He quickly pulled my trousers down and masturbated me. I came very fast. This felt like something of a violation. Many years later, when I was infinitely more sexually experienced, something similar happened to

me. Though similar is not quite the word I want. Rather, the situation had some analogies with my experience with G.

A home help had come to work for me by the name of J. I pretty soon realized J was an emotional and psychological mess. When a young child, she had been rejected by her parents. Or at least she believed she had been rejected. She had been sent to several sets of foster parents, by all of whom she had been seriously abused, usually physically. Her back still bore the scars from where she had been thrashed with a poker at the age of eleven. Another of her foster parents had regularly whipped her. When she was nine, she had been seriously sexually abused by her cousin. These experiences had given J a somewhat morbid preoccupation with her own life history, and also an obsession with the more eccentric, more apocalyptic side of Christian spirituality.

It is interesting that all the women with whom I have been sexually involved have had a history of abuse, whether physical, sexual or emotional. Emotional and psychological abuse can be just as damaging as physical or sexual abuse. Perhaps women who have had such experiences are attracted to me because of my own physical weakness and vulnerability. Perhaps they think they will be safe with me...

When J first came of the scene, I was chasing after A, who was at the time one of my personal assistants, and it took a long time for it to dawn on me that J was completely besotted with me. When she was saying goodbye, she would kiss me. These kisses became progressively more sexual by the day, and I could see J getting really turned on, but with a characteristically male naïveté, I treated it all as a bit of a game. A power game...

Then one morning, when J was working here as a home help, one of my personal assistants phoned in sick. I suggested to J that she come over the evening, and cover for me: to give me a bath and cook me a meal. J was willing and able. After I came out of my bath and I had dried off, we lay together on my duvet on the bedroom floor and snogged. Suddenly, overcome of an excess of sexual passion, J flung her clothes off, jumped on top of me and began furiously fucking me. For some reason, I found myself lying with my head under my armchair. I remember lying there,

looking up at the rosary, which I always keep hanging on the arm of the chair, and J was bouncing up and down wildly on top of me, but she seemed curiously far off, and I was lying there, thinking: 'How did I get into this one?'

[...] One morning, I remember it was a Monday morning about half ten -at this point we hadn't had sex together for two or three weeks -I told J my groin was really sore, and could she put some fungicidal cream on it. She pulled my pants down. By the time she came back with the cream I had an erection. She spent a long time massaging the cream into my groin. My erection was now enormous. J put her hand on my penis and said 'Shall I do it?' I said 'Yeah, go on'. And so she masturbated me, right there on the floor, just outside my bathroom. I came almost immediately, much turned on by the strangeness and incongruity of the situation. And afterwards. ..that certain unmistakable feeling of sordidity.

[...] I have spoken of the vulnerability of the disabled person. In the relationship between client and personal assistant, the personal assistant is often equally vulnerable. She is doing intimate things for the disabled person. Dressing and undressing, bathing, taking to the toilet, cooking, feeding. And it's all being one in a home environment which is cosy and domestic, very different from, say, working in a hospital where the whole atmosphere tends to produce a feeling of clinical detachment. This was very apparent in! my relations with K. K was the first person I had been able to employ directly. She was also the first woman to work for me. Up until then, my care package had consisted of community service volunteers, all male, who had been chosen for me. K had also experienced a history of quite serious abuse. Her husband had regularly raped her, over a period of years, sometimes two or three times a night. When I met her, she had been divorced for ten years, and hadn't had any sexual involvements in all that time. I tend to attract women who have long repressed their sexual energy. K and I got on excellently from the start. We had an instinctive rapport.

At the end of our first week working together - I remember it was a dark evening in early January - K kneeled on the floor to kiss me goodbye. I kissed her back. We put our arms around each other and kissed on the lips. I could feel a sexual opportunity arising. I half-pulled, half-guided her

down on to the floor beside me. Our lips met again and again. My hands began to explore her clothes. And so, one thing led to another, and about a quarter of an hour later, we were making hot, passionate love.

There followed a few months of bliss. K and I were madly in love. She was nominally working for me as a personal assistant, but she would always stay much later than was strictly required by the demands of the job. We would talk and chat and gossip, and drink Earl Grey tea, and kiss and cuddle and hug and make love, and generally do the things lovers do.

At weekends, she would take me over to her place, and we would play Trivial Pursuit against her two sons, who were both in their twenties, and we would always win, because I always knew all the answers. And then K would cook me a late supper of fish and garlic potatoes, and we would drink Lambrusco together, and I would feel all loved and warm and secure. On Sunday mornings, I would wake in her big double bed, and we would make love. K was really into straight sex, which I found difficult. K was always on top which meant she had control of all the activity within the sexual act, whilst I lay beneath her, concentrating on trying to come. I never found it easy to come inside her, and K would sometimes get annoyed when I couldn't. But we were so much in love that this was only a very minor irritation to us. When I look back on it, this seems like a desperately innocent phase of my life. Our halcyon honeymoon was abruptly ended by a disastrous Italian holiday. [ ...]