

Chapter Four (in *The Sexual Politics of Disability: Untold Desires*, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 87-120)

## **Four**

### **Sex and relationships**

#### **Introduction**

A range of issues are raised by the practical experience disabled people have of sexual relationships. It is necessary to avoid an essentialist approach, where disabled people's sexual problems are seen as being an inevitable outcome of their impairment, or where attention is solely focused on physical incapacity. Our research indicates that the major problems are the outcomes of prejudice and discrimination, not individual deficit. Impact of impairment on sexual function will not be extensively discussed in this context, both because it is the topic of much work elsewhere, but also because it is not the causal factor involved in disabled people's experience of sex and love. We need to replace the prevailing medical model of disabled sexuality with a social model which is sensitive to what disabled men and women say about their lives, and not based on the preconceptions of non-disabled professionals.

Policy and provision around disability often neglect to consider sexuality as one of the basic human needs. While housing, transport, education, and other needs are dealt with, albeit inadequately, consideration of social and sexual factors is not high on the welfare agenda. Disabled people in day centres or residential homes are often denied privacy, or the opportunity to form emotional or sexual relationships. This failure to prioritize matters which are highly significant to most adults, including most disabled adults, reflects a failure to consider disabled people as fully human. Just like elderly people, disabled people are not seen as having sexual needs, and provision consequently neglects this. Furthermore, neither disabled people nor elderly people are fully gendered. The typical situation of providing three public lavatories, for gentlemen, ladies and disabled people, is a symbolic representation of the degendering to which disabled people are subject.

In this chapter we will discuss the range of experiences of sex and love. First, we will look at the issue of meeting partners, and subsequently we will discuss disabled people's experiences of relationships. We then move on to sex itself, first demolishing the prevailing phallogocentric construction of 'fucking', then looking at the ways disabled people are having sex. Finally, we will briefly discuss parenting.

## **Meeting partners**

While the disability movement has always opposed segregated education and residential institutions, it is ironically sometimes the case that such contexts have provided the opportunities for relationships for disabled people, as Stuart says: .

'I went to a college for disabled students and I am aware that some students who did not have a great range of movement actually had help from some of the assistants actually in positioning, say, and encouraging relationships, but at the same time they did that without the knowledge of the senior staff, they just ignored it. I think in that sense it was very very positive and you had a lot of disabled people formed relationships with each other. In some cases some formed long-lasting relationships. These were heterosexual relationships.'

It may well have been different for lesbian or gay students, and indeed some women who had attended the same college felt that some sexual activity had verged on the abusive. Moreover, despite potential social benefits of segregation, the overall opposition of disabled people to special schooling cannot be overemphasized.

In Chapter 1, we outlined the major barriers which restrict disabled people's opportunities to meet people for friendship, sex, or romance. Inaccessible public transport, inaccessible pubs and clubs, and inadequate income can all prevent involvement in the interactions taken for granted by non-disabled people. Disabled people are not often welcome in contexts where sex is on the agenda. For example, night clubs and social venues may aim to cater for young people, fashionable people, and beautiful people. Steps, narrow entrances, flashing lights,

smoke and loud noise may all prove barriers to disabled people's participation. Many gay men meet in saunas or at public cruising grounds, which may again be inaccessible or unsafe for disabled people.

Lesbians increasingly meet for outdoor or sporting activities, which may deter disabled participants.

Possibilities such as phone lines and lonely hearts columns may be an alternative option. However, these may be inaccessible to people with visual or hearing impairments. But Patrick found that telephone ads were convenient:

'..being partially sighted has influenced this. Most [lovers] I have met through personal recommendation socially, or I've met one person through work. But the vast majority have either been through answering telephone ads. You just become a member of one of these phone services, and you just answer ads on there, I prefer this to actually writing letters, with "photo appreciated", really makes me run cold. I have done a few of those standing trying to look somewhat sexy in a phone-box-type thing, it's not a fun way to spend your time, but I have done it. So I've been out with lads mostly through phone things, met a few via computer as well, chatting via computer, there is computer equipment, instead of talking you sit and type to the other person, you can see what they are saying back to you. I've only once actually gone and picked up in a bar, going home with him, that was one night and that was it, 'I don't like doing that, bars are usually dark places in my experience.'

The language of contact advertisements is often romanticized, in terms of attractive people, with luxurious lifestyles and high sexual desirability, including physical attributes. This tendency to exaggerate strengths and play down the very human faults and failings of the advertiser may be a deterrent to disabled people, who may feel their impairments will disqualify them from involvement in such negotiations. Alternatively, careful information management is required in the early stages; Bill, a gay man who has met lovers via adverts, pointed out:

'I also can't imagine many replies to letters if you are 100 per cent honest, and say "Oh, by the way I take fits".'

In general, disabled people who could minimize their impairment or 'pass' for normal were more successful in meeting partners, ..as with Ben's experiences:

'I can get out of the chair, take a load of painkiller and go to a sauna, and have really good sex, and get back into the wheelchair. I just don't meet lovers. Rarely do I have anyone coming on to me. [...] I've been having more sex out of my wheelchair. If I'm in my wheelchair I hardly ever pick up. OK, I picked up once at a conference, but generally speaking I don't cop off in my wheelchair. At a Gay Men's Week holiday I was surrounded by 68 gay men and various people I was having conversations with were telling me "I think you're a really horny guy, let me tell you about the other guys I want to get off with this week You know I just got off with this guy and tonight I hope to be sleeping with this other guy, I think you're really horny too." Well, what about me then? When are we going to get together?'

If contact remains limited to correspondence or telephone conversations, it can represent only very partial satisfaction. For example, Mark had found such contact frustrating:

'A lot of times I have had to try and hide my disability. I haven't found it easy to find lovers. I have telephone the switchboards and spoken to gay people to ask if they can help me *meet* gay people. No such luck. If I want to talk, fine, that is as far as it goes'.

One area where these problems are minimized is in the personal advertisements section of disability-related publications, such as Disability Now, which has a large range of disabled people seeking penfriends, friends, lovers and partners. Our current research cannot say whether disabled people are turning to such sources of social contact because conventional leisure and social environments are inaccessible, because they have experienced rejection in non-disabled settings, or because they are specifically seeking disabled companions.

One of the difficulties for disabled people is lack of self-esteem, which often inhibits successful social contact. This, combined with the embarrassment many non-disabled feel about disability, contributes to major problems, as Michael told us:

‘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 the time they are afraid of offending me. 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 I of do they fancy me or are they feeling sorry for me. If and when I have a one-night stand, it's usually with somebody that I know already, so I don't usually have that problem.

'I am not the most forward of people, in fact it's usually been the case that I've been approached rather than I've done the approaching. It is very hard work, but I think, if I don't feel good about myself then 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 I be rather than *doing* something about it.'

It's important. to distinguish between meeting people for sex, and having love affairs, forming relationships or meeting partners. For gay men especially, the former is likely to be more straightforward than the latter. Nigel told us:

'I meet gay men in certain public toilets. .. I have gone cottaging in my wheelchair’.

However, many people are looking for more than sex, as Jeremy discussed:

'I met him through a dating agency. I wanted a boyfriend because I was fed up with -not for the last two years, but for about a decade -the only sexual experience I was getting was through cottaging, vile one-night stands from people that you meet in clubs, because I still go to a lot of

clubs and pubs and stuff. I just wasn't satisfied with it all. A relationship I always thought was not going to be me, because who would want a relationship with someone who was disabled? So it still features very much. Whatever relationship I have that is sexual, I still really think "Am I enough?"

Finally, there are of course cultural variations around meeting partners, which have particular implications for disabled people, as Jo told us:

'I'm not opposed to an arranged marriage, cos I think my mum and dad would do it very well. I would want the astrological thing to be taken into account, and I think they could choose what was good for me. Although if I didn't like it I would accept it. The one thing that pisses me off though is that my mother thinks it is important to let potential partners know in advance in the advert that I am disabled. Now, I think this is not at all necessary, and what kind of weirdos will come knocking if that is announced. Yet my parents think they are protecting me by advertising that I have a disability. They don't realize how offensive this is.'

## **Having relationships**

Obviously, disabled people, like most non-disabled people, are looking for emotional involvement, rather than just sex. However, it is common to find that people do not expect disabled people to have feelings or desires, or to be looking for partners: two interviewees with learning difficulties identified this negative assumption:

Andy: Because we have learning difficulties, we don't have feelings like people who are classed as normal ...

Paul: People who are classed as normal think people with learning difficulties aren't capable of having sex or relationships ... but we should all be able to make our own decisions.

*TS: Do you think that it's a basic right for people to have relationships and things?*

All: Yes.

Andy: If they want it.

Andy: It's not how you look ... the clothes don't make you ... it's yourself ... because you can wear a three-piece suit and be a right dickhead. You can wear jeans, T-shirt, things like that, and ...

Paul: ... be nice as nine pence.

Andy: It's what's inside that counts.

Often, it is assumed that disabled people will form relationships with other disabled people – will 'stick with their own kind.' Disabled people do form partnerships with non-disabled people, but there are sometimes difficulties with this, as Binnie found out:

'I was brought up in the deaf community, my mother and father are deaf, my first language is Sign Language, I met a partner, everybody was actually shocked, because he was hearing, he wasn't deaf. I met him on holiday, I was there with the deaf group, I met him through deaf people. I was with him for four years, but eventually we realized we were living parallel lives, he was very much in the hearing world, and I couldn't get into that twenty-four hours a day, seven days a week, so of course there were other reasons, but personally I couldn't be with him all the time, I felt I needed time with deaf people sometimes, and he felt he didn't want to be part of the deaf world, so that's how we grew apart. I'm not saying that I would never go with a hearing person, but if it happens, it happens.'

Neil and Sue are both disabled, although Sue has an invisible impairment. They found other people were surprised, intrusive and curious about their relationship: several friends and colleagues found it 'inappropriate' that a man with visual impairment should have a relationship with an attractive woman:

Neil: Yeah, we were going down the street one day, I was doing the training for work course, [ ...] one of his work colleagues happened to drive past us and she mentioned that to him, and he said to me, the next time I was in, 'Why go out with Sue, anybody would do you' ...

Sue: He said 'I hear Sue's good looking, what are you doing with her because it doesn't matter, anybody would do'.

Neil: My pal George, has been asked by a few people 'Is Neil's partner blind?', and there's this automatic assumption that I'm a blind person,

and therefore my partner must also be a blind person, and I think that has even happened out in the main street, people have asked me that, you've been there, haven't you?

Sue: Loads of people feel they have the right to ask you as well, that's what gets me. The first time we got together, people were always. ..it was if we were public property, people were always coming up and talking to us in the pub, and we obviously didn't want them to be there, we seemed to attract every drunk in the place, which I had never experienced really before, and with Neil, he's almost like public property, and they feel the right, they have got the right to ask you personal questions.

For some disabled people, the ultimate goal is to be in a relationship with a non-disabled person, because this represents total acceptance, total validation as a human being. Frances highlighted this:

'I think the other issue is that some younger lesbians have said to me that if they had "done it" with a lesbian (or a man or a gay man) it meant that their disability was accepted and that they considered themselves to be in a higher ranking of disability, i.e. it meant to them that their disability was not as severe as someone else with a severe disability who had not had sex. It is almost as if to have sex as a disabled person is "Phew, I've made the grade and joined the club."

This seems to us to be a negative perspective, and denies the value of disabled people, as Stuart suggests:

'It's almost like a victory when disabled men go out with non-disabled women. I should not speak for all disabled men since it is unfair to generalize but they perceive going out with a non-disabled person as making life easier, because life is difficult, when two disabled people go out together it is bloody difficult'.

Certainly there are practical benefits of having a non-disabled partner, and the barriers faced by disabled couples are very significant, as Stuart goes on to say:

‘Like getting out to go to a meal, you have got to book two taxis, it’s incredible, it really is, myself and my partner we hardly ever go out because it costs so much to go out. Like on British Rail, we cannot travel together (as two wheelchair users), we are banned, British Rail said we cannot travel together and I have written to them recently to say, look, myself and my partner need to travel together and they said you can’t, and it’s just so dumb, I mean we cannot even be a family in that instance, although obviously we fight and I think we will get results, because it’s just so blatantly wrong. Going on holiday is a logistics nightmare, we try to find a place which allows you to have wheel-in showers – it’s almost impossible, and the very cost of taking two personal assistants away, and you have to pay that yourself, it’s very hard for two disabled people to go out together, but it is possible’.

However, having a non-disabled partner to help out may place a strain on the relationship. Ben said:

‘Because most of us, if we have a partner, they are involved in some aspects of care for us. I think we feel we have got to take care of our lover or partner, we mustn’t upset them because they will withdraw a lot of their goodwill and support, but if we are being as fulfilled as we would want to be, if we do want to have other sexual partners, we know it’s going to make life difficult for us and we are dependent on them for help’.

As we have suggested earlier, the element of physical dependency in a relationship, in the absence of a third-party personal assistant, may well make things difficult.

People who become disabled later in life may find that impairment interferes with the social networks, and personal relationships, in which they are involved. These psychosexual consequences of impairment are among the most difficult consequences of traumatic injury or disease. Evidence suggests that, in heterosexual contexts, disabled men are more likely to maintain their relationships, while disabled women are more likely to find themselves abandoned by their erstwhile partner. One of our respondents suffered extreme unhappiness and jealousy, because her partner took other lovers, because 'he wanted to make love to a woman

who could open her legs properly'. She felt trapped, because she depended on him as her main carer:

'I cannot describe how awful it feels sometimes, 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.'

Her husband said he could not leave her because 'he thinks he can meet my physical needs better than anyone else'. If she had been non-disabled, she would have left and started again, but did not now feel able to do this, because of her physical dependency on her partner, but also because she 'did not believe anyone would want me as I am'.

When a non-disabled partner feels they are 'needed' by the disabled partner, this may sometimes be to bolster their own self-esteem, rather than reflecting an actual reality. Disabled people's supposed 'vulnerability' and 'dependency' may be less threatening than the independence of non-disabled partners. However, this is far from the truth, as Paula shows:

'Perhaps they [my partners] thought that I was more approachable. I am being very cagey when I say that, maybe they thought that I was an easier catch if you like, because of my disability. I couldn't run away as quickly. Ha! I can remember in one relationship a man said to me "You need me" ... I went "I need you like I need a hole in the head!"'

There are good reasons for disabled people, especially women, to be suspicious of the motives of non-disabled people who want to have relationships: the following is a quotation by Ann, from an American collection (Bullard and Knight, 1981:20):

I find that I am often suspicious of the motives of men who are attracted to me sexually. That is, some men want to be caretakers; some men can't find able-bodied partners (and assume that disabled women are also unable to find partners). Other men are sexually intrigued with disabled women, believing they will have a 'kinky' experience; some men want a

strong 'mother confessor' figure they can depend on or want a woman who will be totally dependent on them.

Although we have explored difficulties with making and maintaining relationships, and will go on to discuss abuse in the next chapter, we do not want to reinforce the idea of disabled people as victims. An account which focuses solely on the very real dangers of abuse and experiences of barriers runs the risk of one more presenting sexuality as a problem for disabled people. Therefore it is important to state that, issues of power and discrimination notwithstanding, our research shows that positive and fulfilled sexual lives are a reality for increasing numbers of disabled people.

For example, the development of a positive disability identity and the opportunity for social exchange presented by the burgeoning disability movement has opened up many possibilities. Many disabled people are ending their isolation by their political or cultural activism, and are forming strong and happy relationships as a result. Many people spoke of an initial tendency to avoid other disabled people, and to seek non-disabled partners. However, this had been reduced in the case of people who had 'come out' as disabled, and developed a positive identity. The fact that other disabled people would understand their experience of social oppression was a key benefit for people seeking disabled partners.

Disabled people's relationship needs are normal and straightforward, and impairment is never an insurmountable problem, as Bill states:

'I want people to realize that epilepsy is not a mental illness and never has been, and it does not usually form a barrier to two guys having a meaningful relationship. I had a relationship last eleven years. The world today has too many taboos, and it is time that someone made it clear that those with epilepsy are not unclean. I'm not angry that I have it, I am just an ordinary guy who had a worthwhile relationship and would like another.'

## **Fucking ideology**

There is a sense in which 'sex' in many cultures is synonymous with heterosexual penetrative intercourse with male on top of female. This myth is so dominant that it assumes the status of an ideology. While it is damaging generally to healthy sexual relations, and no doubt is responsible for the limited sexual pleasure that many women derive from heterosexual experiences, it is particularly oppressive to disabled people, who often cannot operate according to 'fucking ideology', because of difficulty with positioning, erectile dysfunction, etc.

Robert Murphy argues that men are more affected by the effects of paraplegia or tetraplegia on sexual function than women. He talks of impotence as akin to castration, and views alternative forms of sexual expression as inferior to penetrative sex: 'Whatever the alternative, his standing as a man has been compromised far more than has been the woman's status. He has been effectively emasculated' (Murphy 1987: 83). Murphy seems here to be making certain assumptions, based on perceived gender roles and expectations, which we feel are highly subjective, and in many cases sexist (1987: 82):

But unlike men, women need not be aroused or experience orgasmic pleasure to engage in genital sex, and many indulge regularly in intercourse and even bear children. ...Paraplegic women claim to derive psychological gratification from the sex act itself, as well as from the stimulation of other parts of their bodies and the knowledge that they are still able to give pleasure to others. They may derive less physical gratification from sex than before becoming disabled, but they are still active participants. Males have far more circumscribed anatomical limits.

Murphy's view of male sexuality seems particularly prevalent. Popular notions of disabled masculinity focus obsessively on perceived impotence and lack of manhood. For example, *The Sun* newspaper headlined a story about the slow recovery of actor Christopher Reeve from spinal injury with the (supposed) quote 'My Supermannhood is still working' (*The Sun*, 23! February 1996, p. 11). *Lady Chatterley's Lover*,

and films such as *Waterdance*, *The Men*, *Forrest Gump* and others reinforce the idea of disabled men being excluded from sexual activity because of erectile failure, and consequently of being less than men.

The phallocentrism implicit in these assumptions is not limited to British or American culture. A study of the sexuality of paraplegic men in Hong Kong drew similar conclusions (Pearson and Klook, 1989: 286):

The sense that sexual behaviour not involving intercourse is second or third best, or that sexual expression should be stopped altogether, is frequently shared by the physically disabled person, particularly those who have become so through an accident in adult life. Their ideas about sex and the nature of sexual satisfaction were formed at a time when they were able-bodied and they tend to retain those attitudes even when they become clearly dysfunctional.

In this survey such beliefs caused great distress to disabled respondents (Pearson and Klook, 1989: 289):

Data showed that all respondents regarded genital contact, the insertion of an erect penis into the vagina and ejaculation inside the vagina as essential and normal practices and the ultimate goal of sexual activity. Failure to perform these sexual acts was regarded as occasion for great sadness and regret and an indication of the total or partial cessation of a sexual life.

Leonore Tiefer is a urologist who is very critical of the medicalization of male sexual dysfunction, and who has written with wit and wisdom about aspects of sexual politics. She argues that human sexuality has been reified -for example, with the notion of the 'human sexual response cycle'. Furthermore, much sexology is more to do with patriarchal and heterosexual ideology than any actual appropriate or effective sexual functioning. This narrow notion of normal sexuality - which is focused primarily on the male erection -is detrimental to the sexual and psychological health of both men and women. In her article on the medicalization of impotence, entitled 'In pursuit of the perfect penis', Tiefer discusses the negative outcomes of this fucking ideology, and the

way that it is promoted by urologists, manufacturers of penile implants and media, and welcomed by many men and women as the explanation and solution to their 'problems' (Tiefer, 1995). In conversation with one of the authors, Tiefer has confirmed that it is often disabled men and their partners who come to her clinic, and who are most concerned with restoring function.

We would argue that disabled sexuality is all too often reduced to a question of male erectile function, and that this approach penalizes and problematizes men with impairment in an unnecessary and painful way. The mechanistic approach to sexuality underlying this conception is epitomized by some of the work of SPOD (Sexual Problems of the Disabled), which gives advice on sex aids such as artificial penises and vaginas (*Disability News*, February 1993: 16). For most disabled people, it's not how to do it which causes the main problems, it's finding someone to do it with. Problems of erectile function are more easily resolved -by medications such as Papaverine, or by vacuum pumps or implants -than problems of isolation and exclusion.

What is more, such an approach often ignores the experiences and desires of women, with or without impairment, and reinforces a patriarchal and heterosexist construction of normal sexual activity. A recognition of the continuum of sexual practices -of which penetrative sex is only a part - and a greater willingness to embrace diversity, experimentation and the use of sexual toys and other alternative techniques -would be of value to all sexually active people, not just to those who happen to have impairments. Don Smith writes in an American collection (Bullard and Knight, 1981: 16):

I felt asexual for a long time because a man's sex was supposed to be in his penis, and I couldn't feel my penis. So that contributed to my feelings of being asexual; it didn't occur to me that it felt good to have the back of my neck licked, or that it felt good to have my arms stroked lightly. Stroking the wrists, then to the arms, then up the arms, is a sequence that I've since learned can be very exciting.

Sexologist Milton Diamond writes about the importance of doing away with false expectations (1984: 217):

do away with the 'myth', which, in essence, states that the only satisfactory means of expressing oneself sexually and achieving satisfaction is with an erect penis in a well-lubricated vagina. For the able-bodied as well as the handicapped, sexual satisfaction is possible without these practices and in fact, may even be more satisfying. Hands, mouth, feet, and any body part may be used any way to achieve satisfaction, and one means is not, a priori, to be preferred over another.

Some respondents discussed such sexual adventurism, and suggested that their sex lives may actually have improved as a result of impairment: see the account by Penny (pp.203-5), for example. However, for others sexual experimentation and alternative sexual acts may not be a straightforward choice: there may be problem of embarrassment, or of guilt – finding alternative ways to have sex may involve breaking taboos. ‘If the function of sexual expression is private genital satisfaction, then that takes precedence over public approval, and if the purpose is to give or receive love, then that is not dependent upon certain formulas of performance or public acceptance’ (Diamond, 1984:212). Unfortunately for our respondents, they live in Britain. In our view, the prudish and hypocritical attitudes of British society around sexuality are as much a problem for disabled people in Britain as the issues of impairment which they experience. A leader article in *The Independent* newspaper argued that ‘when it comes to nudity, the British are the most puritanical in Europe’, and that Britain had changed little in the past century: ‘We are still oppressed by Victorian prudery, still a country of bathers who struggle under big towels to put on 10-gallon shorts, a nation more comfortable dressing up in period costume than showing off our birthday suits’ (3 November 1995). A recent Australian documentary on disability and sexuality, *Untold Desires*, was notable not just for the positive experiences that the disabled interviewees recounted but also for the frankness and openness with which sexuality was discussed.

It is important to point out not only that sex can consist of more than penetration but also that sex is not the most important aspect of many relationships, and that life can continue during celibacy. Our highly sexualized (if equally prudish) culture contributes to negative judgements on people who are not sexually active. For example, while disabled lesbians may not experience the same phallocentrism discussed above, they certainly reported pressure to be sexually active. Frances said:

'As I have got older, I have learnt that a partnership is not just based on sex, although it is a very important component. But I think that being disabled and a lesbian puts a great deal of pressure on us, certainly when we were younger, to put a lot of emphasis on the sexual side of a lesbian relationship in order to prove that we could as disabled people be attractive and able to have a partner. It could be a status symbol and enhance our own esteem.'

## **Having sex**

First experiences of sex are rarely wonderful or fulfilling. Some of our respondents reported mixed feelings, some felt very uncomfortable. Jeremy said:

'Icebreakers had a party one night. I was sixteen or seventeen and I'd met a friend, a bloke and so we went to this party together. I had my first French kiss. This bloke I hadn't spoken to before came up to me and stuck his tongue in my mouth and I was just so shocked. I didn't know you did that when you kissed, didn't know that you put your tongue in someone's mouth. I was disgusted. I wasn't drunk, I was just so out of my depth and didn't know what the rules were.'

Some felt a pressure to perform, like Eddie:

'I think I lost my virginity when I was fourteen. I tried to do it, probably couldn't manage to do it, although it made me think I did, because I haven't got feeling in my penis or anything, therefore, although I could get semi-erections, I couldn't tell if I was in properly. She was older. It was like an organized thing. I thought she was a prostitute, but I didn't

pay her. Whether my friends did or not I don't know. It was a very unpleasant experience. I don't know whether my friends thought they were helping me out, or whether they were mocking me, because that's what it sounds like, because sex was supposed to be a really wonderful thing and this wasn't at all, I mean it sounds awful but it was like shagging a piece of dead meat. And it meant nothing to her and that hurt me.'

Others, like Gloria, report the joy of finally finding their true sexuality:

'The woman I had my first sexual relationship with was so wonderful. Such a positive experience, even in my most OK times with men, I had never experienced, you know. It was such a celebration of her body which was so wonderful, so familiar. It made me realize this is what I should have done twenty years ago. But this was not an option – especially under the auspices of the Catholic church and perversions.'

Because of impairment, disabled people may have to take more care when having sex, or may be restricted in what they can do, as these comments from Ruth, Pauline, Sara and Zebedee indicate:

'This generation of lesbians talk about the mechanics of sex a lot more. I mean, in terms of sex, the thing that still worries me more than anything else, is some of the stuff around practicality, because of pain and tiredness, and how that is resolved, and how that is negotiated within a relationship. It is something that is very difficult to negotiate in a relationship. It is something that is very difficult to negotiate in a relationship because you worry about satisfying the other woman, and therefore being good enough for her to stay with you.'

'Sex can be difficult due to severe pain. Being aware of positions I can and can't do helps. Being stuck in a position or having to stop half way through due to pain or because my joints have locked or because I'm exhausted are complications I experience. [...] What is important for me is having a relationship with your sexual partner which enables you to stop. To consider your needs, to share anxieties without becoming uptight about sex or deciding never to have sex again. [...] My partner sometimes needs to assist me to undress and make myself ready for sex.'

This, for me, means I am supporting my partner to understand that I do with to have sex and can have sex, but just need a bit more time and assistance.'

'I adapt around this problem, choose positions that don't cause pain. I have had problems of muscles cramping and legs jerking occasionally or migraine-type pain in my head during sex. If this happens I stop, take painkillers or ask for a massage to continue when I'm better'.

'I have no difficulty in having sex. I didn't have full sexual intercourse until I was in my twenties and the reason for that was because I hadn't worked out that I need a girl to go on top, because I cannot get on top of her. I hadn't worked that out and hadn't had a girl close enough for me to sort it out, but since then I have no problems whatsoever and of course there are always hands and your tongue and that sort of thing, although my generation doesn't tend to use tongues quite so much'.

Other people could not predict how they were going to manage with sex: some days it was straightforward, at other times it was difficult or painful, as Nigel suggested:

'It is difficult for lovers as I don't know how I am going to be, I cannot predict what my needs will be. Lovers have to ask what are the ground rules for the day. One day at a time, what was all right yesterday may not be all right today'

Sometimes these physical issues made the disabled person feel disempowered, as with Michael:

'A lot of the time I find myself being on the receiving end. There are times when I would love to be on the active side of things, but I find it physically more difficult to give rather than take. I would love to be able to do it stood up, you see it on films, and it's just not possible. It's very difficult to find a suitable position, actually me lying down with the person sitting on me is the best way that I've found. But I don't have the control. I find it very annoying because I have visions of what I would like to be able to do and find it rather annoying because I can't do it. A lot of the time in a way I suppose I feel rather helpless just lying being

fucked silly and feel a bit powerless in a way, there's that word again, powerless.'

Lack of control over one's body, especially when it involves incontinence, can be stressful, as these comments from Michael and Mark highlight:

'Although I have a lot of control in my mind I don't have a great deal of control over my body and that is a great disability to me. I find that sometimes I enjoy it more in my mind than I do physically doing it, sex in the broadest sense is not necessarily just having it off, there are other things to do. For instance I love giving blow jobs, can't get enough of it and I love that being reciprocated and in a way I find that more satisfying than having it off. My disability does not allow me to ejaculate or, if it does, its usually at the wrong time which has happened before and on occasion I've ejaculated before it has even started, that's a bit embarrassing.'

'I do not need help getting ready for sex, but I do need help getting cleaned up after. It can be very upsetting. After a while a person gets used to it. Often the person (or people) cleaning up are rough; very rarely gentle.'

Specific impairments may not be a problem in themselves, but may change the way people prefer to have sex: for example, because communication is a vital element in most good sex, deaf people we spoke to reported particular preferences:

Phillipe: Hearing sex relies on sound, on your breathing, heavy breathing and that sort of thing, and you never put the light on straight away, kissing and talking and whatever in the dark, now I can't even see what you'd be saying and I need a little bit of light. Now a deaf person is different, they're straight into it, they'll put your light on and talk and then turn the light off and carry on again. Now hearing [people] don't do that ever. This is different, whatever you are feeling, it might be a boil, so, you put the light on and have a look, OK, right, turn the light off and carry on that's the deaf way, hearing people don't do that, they just say nothing, they might feel the boil, and say nothing and just carry on.

I think there is a difference between the hearing culture and deaf culture: in that deaf culture, people are more direct, they are not going to be afraid or embarrassed to look, they are going to have a look, so 'Oh what's that boil, how did you get that?' Whereas hearing culture people are more polite, try to be more discreet, more uptight about things, there is a difference, a different kind of manner inside. Sometimes I think breathing and hearing people, I've already got my hearing aid off, I can feel this heavy breathing, but I can't hear it I just carry on, but deaf people don't rely on that.

Binnie: One of the differences between hearing and deaf, I agree actually, myself I prefer sex with the light on because I like the visual, I think it's important for me to be able to see what's going on rather than in the dark, I can't enjoy it the same in the dark, but that's my view.

For people with visual impairment, there were other issues around communication, as Patrick pointed out:

'I suppose really the only thing is, I say to people tell me if you're happy or unhappy if I'm doing anything to upset you, I do ask people to speak and say if everything is going fine or going well, because I am not going to be able to see what's on the person's face, is he really enjoying it or not. Depending on what position, you're not going to see their face anyway.'

With degenerative impairment, sexual activity may have to adapt and change, as in Zorah's case:

'I used to be a lot more mobile generally and I miss this - there are few positions I can now use; my hand gets tired easily; and I cannot kneel which I find restrictive. Also I am a lot more fat since I have been disabled - both this and my knee impairment means I cannot lie on top of my lover as I wish to.'

Physical decline sometimes had major detrimental effects on sexual relations. Beth again:

'I needed more help to position my body, I began to feel that I was a nuisance and. that sex was solely for my benefit, although my husband claimed that my disability made no difference to how he felt. He seemed unwilling to discuss my feelings. This made me feel very inadequate and I became reluctant to express my wishes or to take any sexual initiative. Sex became a duty which I still enjoyed, but seemed to be limited to a set pattern of ritual moves performed less often and with little real fulfilment.

There are now physical difficulties in having sex which I mind. I can never do what I want to do without help. Sometimes this is not important, at other times it makes me feel that I am a failure. It creates a physical and emotional barrier which I am powerless to dismantle. It even makes me angry then my husband says he does not mind, it makes no difference to how he sees me. It makes a difference to me, but. I feel as if my feelings are of no consequence, my worth and value are diminished.

Other respondents talked about the benefits to their sexuality resulting from their impairment and physical lack. For example, Paula talked about her lack of inhibitions consequent on her physical experiences of MS.

'Before I got MS I was OK, my sex life was pretty good I suppose but I was thirty and I had MS for eight years before I became multi-orgasmic'.

She felt that her sexual life was more varied and interesting, that she was more likely to initiate sex, and that she had been liberated by having been able to accept her physical difference: her sexual partners also felt freer, and under less pressure to 'perform'.

Similarly, people made a comparison with the development of safer sex, which had shifted attention from penetration to more diverse and varied sexual contact, including touch, massage, and other areas of the body. Because disabled people were not able to make love in a straightforward manner, or in a conventional position, they were impelled to experiment and enjoyed a more interesting sexual life as a result. Paula again:

'I think that they have more imagination, certainly, I've had more *fun* in bed and I don't mean just sexually satisfying, but it's also a giggle, when you find, especially if somebody else has an impairment, you are sorting out what you can do, and it's like *Playaway*, it's just silly and fun and I think a lot of people who do not have physical impairment and do not have to consider what they think they can do, are actually too frightened to confront what they want to do, I mean there's a lot of straight men, without disabilities, who go to other places, go to whores and go to different places because their partners of whatever sex will not enter into the game, and sex is a game, it should be fun, it's not a big serious thing, you don't have to say this is the end of the world, it should be fun, enjoyable, it's like a spark of life.'

Several people felt that they had better sex, felt freer and more equal and derived more enjoyment, from partners who were also disabled. This may be because they themselves felt more relaxed, or it may be because disabled people are better lovers than non-disabled people: there is certainly anecdotal evidence of the latter. Paula reported:

'I just think that, actually, the two probably most successful sexual relationships I have had have been with wheelchair users. Often disabled men are more erotic and caring. The two men that I have had sexual relationships with who were wheelchair users gave me the most mind-blowing sexual experiences that I have ever had in my life. And probably burnt out quite a few brain cells at the time, it had nothing to do with the MS, the neighbours could have complained, it sounded like I was being murdered.'

The suggestion that there maybe distinct advantages to disabled sexuality runs against the assumptions of the sexological literature, and the obsession with erection, ejaculation and orgasm which have defined responses to disabled people's sexual 'problems'. It may also suggest that for these heterosexual and homosexual disabled couples, sexual relationships may potentially be more balanced, more equal, and more open than for non-disabled people. '

## Parenting

### Attitudes to parenting

For many disabled people, their ambitions can be summed up in the phrase 'a job, a partner and a family'. In this section, we will explore some of the issues around parenting, although we do not have the space for a full account. Readers are referred to sources such as Anne Finger's excellent *Past Due* (1991), Campion (1990), and the Booths' book about people with learning difficulties, *Parenting Under Pressure* (1994).

As in other areas, non-disabled people's attitudes are often the main problem around parenting. It would appear that disabled women are denied not only their role as employees in the workplace but also their domestic role as partners and mothers. The powerful stereotypes of dependency and passivity add to the notion that disabled women are cared for rather than care-givers. As Kay states:

'When I am out with my children people always assume they are my helper's children. Folk can't get their heads around the fact that I am a sexual person, a lover, a mother, and a care-giver. I am seen as the one who is cared for. It really annoys me that my motherhood is denied, I have spent eighteen years mothering and a major part of my identity is as a mother. Every major decision I make is based on what is best for my children, yet I am denied the luxury of being acknowledged as a care-giver. The only acknowledgement I have had has been to challenge my decisions, to ask was it fair on the children, to bring them into the world as a disabled woman.'

Many disabled men find the fact that they have fathered children and are capable parents is too difficult for others to accept. Neil describes one reaction to the news of his partner's pregnancy:

'When Sue was pregnant I mentioned it to my supervisor and he just came out with this line, "Who's responsible for that?", partly out of shock and partly it couldn't possibly be me kind of thing, and I just looked down at Ashley (my guide dog) and said "Well it wasn't him" ... I think he realized what he had said, he was a bit apologetic'.

Parenting is probably one of the most challenging notions for society to accept, as it challenges the myth of disabled people as eternally childlike and sexless. Parenthood puts disabled people in positions of responsibility reserved for the non-disabled. Such are the levels of denial, that people will jump to any conclusion other than the obvious one, for example assuming that the child belongs to a carer.

Disabled people are also not perceived to be good parents, and bringing disabled children into the world is seen as being a negative thing as these two respondents with learning difficulties were well aware:

*TS: Do you think non-disabled people are frightened of disabled people having kids?*

Andy: They think that if they have kids they might turn out like them: more of them than us.

Paul: They think we can't cope. But you don't know. Give it a try.

It is also the case that, if disabled people do have children, they sometimes face less patronizing attitudes - are less likely to be infantilized themselves. Rachel Wilson was quoted in *Disability Now* as follows: 'I guess people think that if you're capable of having a baby, you must be normal. A stranger did ask me if the baby was mine. I felt like saying "no, I pinched it".' On the other hand, sometimes becoming a parent means being seen as independent, and therefore leads to being denied services: 'I am a single disabled parent and I am viewed with disgust because of it. Services are refused because you have a child. If you have a child you can do for yourself' (Lamb and Layzell, 1994: 20). There is now important debate about children who are carers for disabled parents, and the prejudice and problems involved (Keith and Morris, 1996; Olsen, 1996).

Another factor involved in the unwillingness to contemplate disabled people's sexual subjectivity is the fear of disabled people joining up with other disabled people, and breeding more disabled people (Humphries and Gordon, 1992: 100). In a century which has seen repeated policies of eugenics, and ongoing concern about the purity of the race, the

spectre of more impaired children is viewed with alarm. One respondent told us a relevant anecdote:

'I heard there was these two people in the supermarket, and they were both wheelchair users, and they had a kiss, I don't know why they wanted to kiss in a supermarket, but they did, and somebody came up to them and said "Do you mind, it's bad enough that there are two of you" ,

This prejudice may be about racial and national purity, or due to cost arguments focusing on the 'increasing burden' to health and social services from this 'deviant' and 'dependent' population. Clearly these fears are subjective and irrational, and can be connected to fears of miscegenation, and of the racial 'other' contaminating Caucasian racial stock. The Human Genome Project will increase the pressure on carriers of 'defective' genes not to reproduce, or to terminate affected pregnancies (Bailey, 1996). It is worth pointing out that by far the majority of impairment in Western societies is a product of accident, disease or the ageing process, rather than originating in the transmission of defective genes (Shakespeare, 1995).

Many disabled people are keen to have children, sometimes also feeling the pressure of family and social expectation, as Eddie discusses:

'I'm a disabled person and I wouldn't have it any other way. Now our relationship has come to a stage, because after four years Jo is saying we should think of getting engaged and with the subject of kids coming along. I still don't know whether I can do it, have sex properly, we've had sex, and she said yes it's quite good and the rest of it, but whether I can actually do the job all the way and produce the goods, can have kids, that's quite important because I would love to have kids. The thing is I have never really produced sperm. I don't masturbate a lot, I certainly wouldn't masturbate to the point where I have produced sperm.

'The whole thing about having kids, the point is a lot of people and my family are a bit concerned, can we produce kids and if so would they be crips? If I produce disabled kids they are going to be real militant bastards, and they are going to take no shit off anybody, and that's the way a disabled guy's attitude should be. It's because all my brothers are

married, and all my brothers have kids, and it's important for my dad, and it's important for me, I want kids, I do want kids. There is still this thing in me, not so much my own feelings but if I can't produce kids. Jo and I have talked about it and she has said if we can't, we will adopt, and then I'll likely find that I some adoption places might be prejudiced because I'm disabled they might think I'm not capable, and that's the other thing, I want kids, I want to be seen that I am helping bring them up, because I am capable of doing that'.

Society may be hostile or ambivalent to disabled people becoming parents, but is perhaps not even aware that disabled lesbians and gays rear children too, as these quotes from an anonymous gay man and from Sara indicate:

'I have competently "parented" kids and enjoyed them. They all turned out "normal", not that gay disabled men are meant to be capable of such parenting'

'People are shocked and wonder if I should have kids, being gay and a cripple, but when they see me with my kids their attitudes change.'

### **Pregnancy and parenthood for disabled people**

The negative attitudes towards disabled people having children create as many problems for parents as the physical difficulties associated with particular impairments. We were told about one disabled woman who asked her medical worker to record her pregnancy as 'unplanned', when it was in fact planned, because she feared negative reactions from obstetric services (Gill Aston, personal communication). Julie Marshall wrote:

'When I became pregnant, my visits to doctors, midwives, and antenatal clinics produced a mixture of emotions. I felt like somebody who was to be "set apart" from other mothers and was ushered in and out of examination rooms with the greatest of speed. Perhaps I may have upset some mothers to be because I was in a wheelchair and my disability was obvious! During the examinations the importance was not as much on the health and well-being of my unborn child, but on the nature of my disability and how I was going to cope during my pregnancy.'

Because of the way her impairment was perceived, Julie was denied the opportunity of having a normal birth. Because of the barriers presented by buildings, she couldn't access ante-natal classes. In all these ways, her experiences demonstrate how social arrangements create difficulties for disabled parents which are not experienced by non-disabled people (just as it was earlier suggested that family planning services are often inaccessible). Neil, as a prospective father with visual impairment, found that at the ante-natal class

'There was a lot of visual aids, cards and diagrams, the doll thing, what have you, (the teacher) found that quite difficult.'

His partner Sue, who has asthma, was keen to take advantage of drugs during labour, in order to minimize her breathing problems, which also went against the philosophy of the National Childbirth Trust classes which they attended. In general, as a disabled couple, they felt out of place with the other prospective parents.

Many disabled parents felt that there was a lack of information, and a lack of role models, and that they felt very isolated as prospective or new parents. Few books cover these experiences. Sue had read and appreciated a book mentioned earlier, *Past Due*:

'There was all these issues, I just felt it echoed a lot of my experiences and my feelings. I read loads of things about women had written about being mothers, but there was very little about being a mother with a disability, I just really wanted to read that, and read that there are times when it just feels awful having a disability and being a mum and there's times when it feels great, I just wanted a bit more of that.'

Following the birth, again there are no inherent problems for disabled people having families. However, there are many social barriers and obstacles to overcome. It is hard enough getting accessible housing as a single disabled person: there are few appropriate houses for disabled people and their families, especially when both parents are disabled. Stuart and his partner had found this:

'With having a family we have to sort out the housing situation because we need a stable environment for our kids to grow up so that we can be proper parents, but there are all the hassles, disabled people in society are just not catered for, like living in a project which was built two years ago by a charity and a housing association and all the flats were designed for single people, are they assuming that disabled people never form relationships, or want a family?'

On the one hand, there is a perception that disabled people are not capable parents, and that their children are consequently in danger. Sue said:

'They couldn't cope with the fact that we might just ring someone up and need them there and then, their flexibility wouldn't allow that, and

On the other hand, basic support services such as personal assistance are not provided. Sue and Neil did not want full-time support, but would have appreciated a back-up service of helpers at times of crisis or difficulty, or example when they themselves had health problems. Sue again:

'I think a sort of an emergency nannie scheme which is run. ..a private scheme, is run where you can enrol where you ring up and say "Look I'm just not well this morning", or "I've got an emergency appointment", and they send someone to you, they guarantee someone to you in an hour. You have to pay quite heavily for that but I'm sure social workers could cope with something like that. They've only got traditional roles for seeing things, crisis intervention, but even crisis I don't like because it's not necessarily a crisis, it's extra support like you would normally get from a family.'

The perception of social services is sometimes that disabled parents risk disaster, and cannot cope. The reality is not that everything is always wonderful and that nothing goes wrong, but that things are usually OK, but sometimes support is required. This balanced perspective is not always forthcoming from welfare professionals. Sue again:

'As disabled people with our particular disabilities we do pick up things and we are more likely to be ill, more than someone else who has a disability, and that doesn't mean anything really, it just means. ..I think disabled parents can have extra problems and that's all right, that's not a failing but we need resources to support us and. ... that can be enabling and empowering, but they can't cope with it at the moment, they seem to think there is problems left, right and centre. I'm not going to go on and pretend it's all super, and that we are just coping wonderfully, we are also we don't, but some of it is just being real parents, and some of it is particular to us, which is why I would really like to meet with other disabled parents who have got issues for themselves and how they found ways round it ...surely the services should be there as resource, that we can tap into, instead of trying to take us over.'

While disabled people were critical of public attitudes, and also of the role of support and welfare services, it was also felt that the disability movement had failed to respond to issues of parenting. Because traditionally there were few disabled parents, and perhaps because parents were too busy to become active in political campaigns, there was lack of understanding. For example, problems of childcare in connection with attending meetings, or the tiredness that comes with having a new baby, were not appreciated by other disabled people.

However, there are also positive developments which are indicative of changing attitudes to disabled parents. For example, there is increasing coverage of disabled parents in the media, including articles focusing on pregnant disabled women, with features in *The Guardian* ('Ready, willing and able', 10 August 1993), *Disability Now*; etc. There are new organizations, such as Parentability and the Maternity Alliance Disability Working Group. A new journal, *Disability, Pregnancy and Parenthood International*, is a forum for support and sharing information.

It remains to be seen how developments in genetic knowledge and pre-natal testing affect disabled people: there is a danger that women carrying fetuses with impairment will face renewed medical and societal pressure to terminate such pregnancies. However, there are positive developments as well. The success of the disability movement,

and the growth of the disability community, means that more disabled people are forming relationships, and inevitably more will choose to have children. For these reasons it is particularly important that parenting is recognized as a disability rights issue, and that the disability movement takes this on board, alongside the other civil rights for which it currently campaigns.

## **Conclusion**

In our research, we asked disabled people what tips or advice they would give other disabled people about sex and relationships. We will close this chapter on a positive note, with their words.

‘Sex is for everyone. Whatever happens, try to enjoy it. Find an understanding person to be with, even if it means waiting. Two disabled people having sex is brilliant because there is more understanding for things like positions and any accidents like wetting themselves.’ [Mark]

‘Be patient with people’s ignorance about the situation. Because if they have had very little contact with disabled people they are bound not to know intimate things like bowel and bladder management, that type of thing, and if you are patient with them, then they are usually quite patient with you.’ [Michael]

‘Because if I’m going to be embarrassed I’ve lost the game, there is no way, there is no way I could continue with this, there is no way I can go into a sexual relationship feeling vulnerable, feeling apologetic, these two things do not make you feel randy, they do not help a sexual relationship by saying "What am I going to say?" and "You can do anything you like with me". No, I don’t want to play that game. No. No.’ [Paula]

‘Trying to communicate what’s going on as it’s happening and not deal with it later. I think communicating is the most important thing really. I think one of the most important things for me is being about feeling bad about not being able to give the things that I would like to be able to give, and sometimes it means my partner is in a position which is not comfortable for her, not as comfortable as she would like to be but it’s

the only position where I can manage to give pleasure to her, so it's a really difficult one that about negotiating what you can manage and how long for.' [Ruth]

'Experiment, try new positions, new games, make it fun. I find not letting my disability hinder me or cause lack of confidence was hard at first, but once the partner didn't seem bothered I relaxed and forgot about it and had a lot of fun, laughs and good sex.' [Sara]

'It's good to talk, share feelings and ideas.'

'Snogging is the best!'"

'Have fun, enjoy what you are doing.'

'If you have a good relationship you can share your insecurities and ideas about sex.'

'Go for it!'

## Anthony

It all started about eight years ago, and in those days things took a long time to come to fruition. Having just moved to a working-class district of the Midlands from suburban Surrey, we felt it was about time we had had children: after all, we had been married and trying for children for three years. Although I was a wheelchair user owing to spina bifida and hydrocephalus, and my partner was 'normal', our sex life was perfectly ordinary. I just didn't produce any children.

Once in the Midlands, I arranged to have a sperm test (on the NHS) at the local family planning clinic: as inaccessible as any building could be. My sperm count was low, but not significantly low, we were told: probably due to the stress of the steps, I suspect. Then we, my partner that is, were referred to the local hospital to see a gynaecologist, whom we saw about a year later. My partner was scheduled, and had, a laparoscopy (a micro-camera check of her reproductive organs) about a year later. It seemed there was no problem there either. It was all moving very slowly and there was apparently nothing 'wrong' with either of us.

I, as a matter of routine, saw a urologist once a year for a check-up on my kidneys, and I mentioned to him the process we were going through in relation to infertility treatment. Luckily, my urologist said he knew someone in Birmingham who was doing infertility research and might be able to help us, and that he'd write a letter if we wanted. We did; he did; and we were seen within months. By going through my doctor we had queue-jumped many years ahead of where we had been by following the women's doctor route. By lucky coincidence, because we had been referred by an NHS consultant, the NHS would pay. My partner's gynaecologist was furious, but we didn't care.

If the NHS hadn't funded it, we probably would have had to have abandoned it fairly soon. Luck was on our side. The Birmingham infertility people took regular sperm tests, and decided to give my partner another laparoscopy (they wanted to 'see for themselves'). Sperm tests are a little tricky for me, especially in an office room that had been cleared of furniture (except for a semen-stained leather chair) and which was littered with soft-core porn magazines. The blinds on the window

were as dirty as the leather chair it seemed, and the small sink in the corner, with industrial cleaning liquid next to it, didn't lift the room out of its seediness at all.

I had another little problem: although I could easily get erections and ejaculate in the privacy of my own home during sexual moments with my partner (or anybody), I couldn't just masturbate to suit the occasion. I do not have much feeling in my penis, and, as such, the pleasure of simply wanking has always been lost on me: two's fun, one is plain boring. Thus my partner and I basically had to make love in this seedy little room -with hospital staff wandering up and down the corridor outside -with no space but a little sofa. The fact that I am paralysed from the waist down made manoeuvres difficult, to say the least. The staff of the infertility unit were oblivious to these problems and there was absolutely no point in mentioning it because it was as it was. Some people lived close enough to bring their sperm in, but we lived over an hour away and that made that an impossible alternative. We struggled on and always managed, except once, to provide the necessary sample.

We had, like most people who cannot conceive, 'inexplicable infertility': there was simply no reason for it. The clinic in its attempts to solve our problem, and probably most people's, would intermittently turn their attention from one of us to the other then back again once no problem could be discovered. My partner was fine and I was fine: I didn't even have a low sperm count, it turned out. The first one -in even worse conditions than Birmingham -had simply been a bad day.

On first arriving at any of these points, we were always greeted with a degree of surprise and always asked the most banal questions possible, like 'Are you putting it in the right hole?' One of the most interesting facets of all our visits was the degree to which the men, who accompanied their partners in attendance at the clinics, felt deeply humiliated at being at the clinics/hospitals. As a disabled person from birth, I had never had the luxury of such attributes as dignity and pride, or been imbued with a sense of macho superiority. The treatment my partner had to endure was often very humiliating and deeply painful, both physically and emotionally, but I had not taken it too much to heart

as I knew that is how the medical profession works (usually unnecessarily).

Arriving at the clinic to be confronted by a man sitting in the corner, waiting to be given a jar to then go and wank in it, with his head under a newspaper so that no one could identify him, was not uncommon and something that only added to the often surreal nature of the experience. The eerie silence that usually filled the waiting rooms could have been cut with a knife and those more middle-class patients absolutely hated it. That these people were reduced to being in the same room with a sad spaz (who they presumed was not a real man anyway) meant it was a humiliation I beyond belief for them: though rather amusing for me, especially if one considers that one in six couples have 'inexplicable infertility'.

Being the totally sexist experience that it is, I was never required to do more than produce a sample of sperm (in my case with the aid of my partner, and in the case of almost everybody else, by having a good wank over heterosexual porn mag). On the other hand my partner was operated on, pumped full of thousands of pounds' worth of drugs, given local and general anaesthetic, and abdominally scanned regularly (sometimes every day for weeks on end). She felt pain, sick, ill and disgusting most of the time. The drugs that were used were to control the size, number and release of ova. Bad enough in itself but if, for example, the doctor went on holiday or to a conference -we were never told -they then just pumped you full of more drugs to put you 'on hold' until the doctor came back!

We started off at the Birmingham clinic with four AIH treatments, AIH being artificial insemination by husband's sperm (good job I was the husband, or they would have had to have changed the name of the treatment). For this they controlled my partner's ovaries with drugs, scanning and every day visits. I, on the other hand, only had to come on the last day and provide a vial of sperm, which I dutifully did, and it was then artificially introduced into my partner's womb via her vagina. The physical and environmental barriers to producing sperm often seemed insurmountable, but at least it was drug-free. The treatments would have cost £100 per go, plus drugs (another £400), but as I've said, thankfully

the NHS (you) paid. Unfortunately none of these worked. As you can imagine, the whole process put an incredible amount of strain on the relationship between my partner and me: sexual activity became totally functional - when it occurred - as we always hoped that we would conceive so that we didn't have to go back to the hospital. That my partner felt ill most of the time, and this was for months and months on end, I didn't help in invigorating a dulled sexual appetite (one of the symptoms of the drugs she was on was that she constantly felt like she was going through the menopause).

AIH having failed, we then moved on to the next stage: IVF (in vitro fertilization) treatment. This is basically the same treatment as the AIH, but with the sperm I produced mixed with the ova in a petri dish where fertilization takes place outside of the womb (the ovum having been extracted under general anaesthetic earlier in the day), and then a number of fertilized eggs/ova are introduced directly into the womb via the vagina a day or two later. This treatment necessitated a stay in hospital and a general anaesthetic for my partner. My partner was put into a double room in a private hospital to start with, but we were later moved as my presence disturbed the other client: I made them feel more abnormal in a situation in which they felt abnormal enough already.

The initial IVF treatment didn't work either, so we went for a second IVF course of treatment. Near the conclusion of the treatment the doctor went to a conference: the treatment (drugs) was extended to delay it, but as the doctor stayed longer than was expected, we were given an AIH treatment instead, for free, at the last moment. Such treatment seemed to be not uncommon. Much to everyone's surprise, conception occurred. At this point, the infertility clinic told us to go to our own local hospital for the monitoring and management of the pregnancy. We did just that, but felt just a little peeved that the clinic just fobbed us off once we had conceived.

The real pressure was just about to begin. Once at the local general hospital, we were constantly pressured to have the relevant tests to see if the foetus would have a disability (i.e. mine: spina bifida). The assumption was that we would, and that if the test showed a possibility of 'handicap' we would have it aborted. We refused the test, and were

then constantly offered it at every ante-natal appointment (there is no date limit on the abortion of a possibly impaired foetus). We didn't refuse the test on the assumption that it wouldn't happen to us: quite the opposite really. We refused the test. Because it made no difference to us whether or not the foetus (child) might or did have an impairment.

The whole infertility treatment system we went through would have been difficult for anybody, but as a disabled person using a wheelchair with a congenital impairment the whole physical process was made harder due to the general belief that it isn't something that people in wheelchairs do (an illogical belief in fact, and in the twisted logic of masculinity). Once my partner had conceived, the whole issue of wishing to have a child that might be like me (have a congenital impairment) was exceptionally difficult for a vast number of health professionals to believe: I was sorely tempted to ask them why they hated me so much that they considered a life like mine to be only worthy of termination. Apart from it being unfair to blame individuals for the collective attitudes of the whole of society, it would only have antagonized them even more than our anti-test stance already did. That we are not religious, less easily dismissible as righteous, only aggravated them more. And, after all, they still had considerable power over us as patients in the pregnancy system. Eventually we became, despite the pressures and obstacles exerted against us, the parents of a wonderful little boy. Would we go through it all for another one? Is he disabled? Well. ..