Chapter Three (in The Sexual Politics of Disability: Untold Desires, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 49-86)

Three

Identity and Imagery

Introduction

In this chapter, we discuss issues of identity: being a disabled person, being a man or a woman, being sexual. We are interested in the feelings people have about their identities, and the way that impairment and disability affect, and interrelate with, other identities. Previous disability studies work has failed fully to explore the meanings that gender or disability have for ordinary disabled people, and we hope the following material will provide some more clues. It is not our intention to offer a developed analysis of the feelings held by our respondents, so it may be that the discussion raises more questions than it provides answers. Although we attempted to include people with a range of impairments, and particularly to reach people with other identities (as black or Asian people, for example), the sample was not representative, and there are voices missing from this chapter which would add important perspectives to the debate: for discussion of these issues, we refer the reader to publications by black disabled .people such as Ayesha Vernon (1996) and the contributors to the Reflections collection (Begum et al., 1994). While lesbian and gay respondents are included within this chapter, a fuller discussion of the specifics of lesbian and gay identities will be presented in the later. chapter on lesbian and gay disabled people.

In the second half of the chapter, we look at imagery, exploring the range of attitudes and stereotypes that are held about disabled people in society. We are also interested in notions of beauty and normality, because these values are often prejudicial to disabled people's acceptance. Yet disabled people themselves are socialized within this dominant culture, and therefore hold conflicting views about desirable partners, and can have negative views about themselves.

Identity

Disability identity

Just as theorists of lesbian and gay identity have argued that it is necessary for gays and lesbians to 'come out', a process of privately coming to terms and publicly affirming sexual difference, so it is suggested that disabled people have to go through a similar process. This is not the same as 'coming to terms with impairment', but is about assuming a social identity as a disabled person, and often about taking on a politicized understanding of disability. While congenitally impaired people may always have been disabled, they may have gone through the period of denial, and still have to go through a 'coming out' process. The following conversation illustrates some of these themes:

Eddie: I was born with my impairment, I had four brothers, none of whom are disabled people. There was my dad, my mother died when I was four, and I was brought up believing I was the same as my brothers [...] I think even if you were born disabled you still have to go through a coming out process. [...]
TS: But you have always been in a family that has accepted you?
Eddie: Yes, they have come to accept the fact that I'm the same as anyone else, can do as well as anybody else, which had its advantages which was not being mollycoddled. The disadvantage was I was never taught anything about disability and the wheelchair, about disability and identity.
TS: You were normal, treated as normal.
Eddie: Yes, I was normal like everybody else and I had the opinion that I was better than disabled people, and I wasn't disabled, and I couldn't pass a full length mirror and I had very low self-esteem as a disabled person. I just couldn't see that I was disabled. I knew I was disabled but I couldn't accept it.

An important point to draw out from this extract is the sense of isolation that individuals, such as this man with spina bifida, may experience in families in which they are the only disabled member: while members of other oppressed groups (women, black people) can expect to find role models, kinship, and support, disabled young people may experience the isolation of being different from family members (perhaps paralleling the experience of young lesbians and gay men). Kit told us:

'I felt angry and I didn't know why, I thought I was the only disabled person in the whole wide world, and again I never went to school with disabled people, I'd never met a disabled person, and I certainly didn't identify with disabled people.'

In some cases, parents and family may actively encourage children with impairment not to identify as disabled. Many respondents echoed Eddie's comments, for example Jeremy, who has a congenital impairment involving muscular weakness:

'I went to the school which was in the middle of the estate, and really I knew I was disabled but I didn't admit it. I wouldn't talk about it, I wouldn't class myself disabled. [...] Despite the fact that I had callipers.'

Jeremy won a scholarship to Dulwich College, but was refused entry because of the school's inaccessibility: subsequently he went to special school and lost touch with all his old friends and suffered a vastly inferior education. His parents sent him to a PHAB Club:

'But it wasn't really me. Because I was still in denial about being disabled most of the time, and if I saw anyone who was disabled I didn't want to talk to them, and if I did talk to them it was as if I was able-bodied talking to them, doing the old patronizing bit. Because luckily my disability can only be visible in certain things that I do. I always thought I was better than them.'

Many respondents felt that people who were congenitally disabled were disadvantaged in comparison to those who developed impairment later on in life, because they were excluded from mainstream social and educational environments and denied opportunities: often this also had the effect of undermining confidence and assertiveness. However, although people disabled later in life would appear to have had all the advantages of so'-called 'mainstream' socialization, many are so devastated by their change in circumstances and status that they withdraw, remain isolated and 'traumatized' by the experience of becoming disabled. Acquired impairment can also mean a life of adjusting to physical changes, as Pauline explains:

'Over the years my disability has affected more parts of my body and I have become much more tired. This means constantly adjusting to what I was able to do, what I am able to do now, and accepting that maybe tomorrow I will either do it the same, different or not at all.'

For those who gain an impairment through disease or accident, it may be a matter of encountering new attitudes, as with Sara:

'I feel that becoming disabled suddenly meant I didn't know about general stereotyped ablist attitudes so everything was a shock. Being able-bodied and then disabled highlighted how differently people reacted to me now compared to before.'

There may also be a desexing process implicit in this change. Sara again:

'I feel the same, but I know others don't. .. people now see me as a non-sexual being with no gender or sexuality sometimes, but to me I'm who I always was, no different. [. ..j I feel others mainly see me as a nothing sort of person. All they see is my disability.'

Some people felt that becoming disabled was about a challenge to one's own attitudes. Patrick commented:

‘I think, of course, if you are non-disabled and you stay that way into your teens or adulthood, then you have very little exposure to disabled people or meeting disabled people, so you probably developed the social stereotypes of “be kind, be nice, and be patronizing” to disabled people. But then when you suddenly become more disabled, I think in a way it can be in some cases even more difficult to deal with. Because people have been viewing themselves as non-disabled and suddenly then become disabled.’

Several people who became impaired later in life felt uncertain as to whether they had any right to identify as disabled. Ronan, who has a colostomy and cancer and is HIV-positive, said:

‘It is very odd, sometimes it feels to me, am I real as a person identifying as disabled, really disabled? […] because it’s not congenital, it’s happened recently […] it’s very real for about six months, and so am I really a disabled person? Sometimes this little voice says “How dare you!”.’

Having made the transition to disabled status very recently, he had a vivid recollection of the differences:

'Oh gosh, as I have said, it's catastrophic, the change that happens, it's almost like you have to that yourself as a new born baby allover again. Yes, you have to parent yourself, you have to nurture yourself, as if you were just new and had to ,be gently eased 'into the world, that's certainly how I felt about myself. For instance, up until Christmas, I was somebody who, despite being in pain twenty-four hours a day, still went disco-ing, and got drunk lots, and had lots of sex, and since then I've been out dancing once, I think, and I don't drink very much, and well, I just take care of myself. I don't go out very much now, and everything is very deliberate, feels like, so that's quite a different thing. I don't take as many risks as I used to.'

Louise felt that acquiring an impairment meant needing to catch up with the learning that congenitally impaired people had experienced: for example, encountering barriers or attitudes. She also felt that she 'wasn't really disabled':

'I know that when 1 first got my orange sticker for my car, and I used to go and shop in Sainsbury's or something, or go and park at the disabled parking spot, I kept thinking that someone was going to come up and say "What the hell are you doing here, you're not disabled" or "you are not disabled enough".

In our experience, because disabled people are made to feel guilty or grateful for any concessions which they enjoy, this feeling of fraudulence is common to many people born with impairment, as well as those who become disabled later, and is part of the internalized oppression discussed in the previous chapter.

Sometimes, within disabled contexts, there is prejudice against people who have acquired impairments, who are not seen as being as disabled as those who have always had impairment. Alternatively, there may be cultural differences. Phillipe discussed the difference between people who came from deaf families, and were born deaf, against people like himself who had hearing parents, and became deaf through childhood meningitis:

'Now because I was from a hearing family, and I was born hearing and then become deaf, so they do look at me differently, there is a difference from their own perspective, and I look at them and think "Oh, profoundly deaf" ...if they have been born from a deaf family, you can see that difference, there is a difference in culture as well, this is generalizing throughout society, but there is hierarchy, it depends upon their own upbringing, the way of life, whatever, it's different from mine, because I have got a hearing manner, inside me, and they have got a deaf manner. I'm not saying that's anything wrong between either of us, which is good and which is bad, it's the way I was brought up and it's the way they were brought up, different, but you can tell the difference. When I'm somewhere with a big group of deaf people, you can see the people who are born from deaf families, and the people who were born from hearing families, you can tell the difference. There was two of us who were deaf, there were people who were at this meal with us, the rest of the group all their parents were deaf, there was just two of us with hearing [...] we were all signing away, sometimes, you can't interrupt, I couldn't join in because we felt as if we were a bit out of it, we waited until everyone else had finished talking, when It was an opportune time, then we would jump in with the conversation, so we felt we were always a little bit behind all the time, because they were there busy chatting away and talking at the same time and we felt as though we were waiting before we could actually get into the conversation, it is definitely different. Very interesting their way, the way they would eat, the way they talk, timing, it's totally different from us two. We waited until we had finished eating and then we would speak, sometimes they would be actually eating and speaking at the same time, there's a bit of influence between us all, I know that, but you can tell the difference between people who have got the deaf manner and some that have the hearing manner, that's my view.'

Disabled people, whether their impairment was congenital or acquired, looked back at the period before coming out as a time of pain and self-loathing. Eddie told us:

'There are h lot of things about me to do with my identity as a disabled person, not coming to terms, not coming to accept who I am. A lot of these problems, with the fighting and all that, was part of the gradual acceptance: I was an alcoholic at eighteen, and I was addicted to gambling, I think this was all part of the punishment process, I hated myself, I couldn't stand myself, I thought I was the ugliest thing around.'

When Paula was diagnosed with MS, she went through a period of internal conflict and denial:

'I refused to be sick, it was like, I am not going to let this beat me. But I also didn't have a boyfriend for two years, nobody asked me at all. It was because I closed down on myself, I had ceased to perceive myself as an attractive human being, I couldn't project myself, and I just wanted people not to notice me. I wanted to disappear, and I think it took me many years to actually get to the stage of saying, well it's here, it's part of who I am, it has formed a lot of what I have done. So I am disabled, it is not a character trait that I can work on so, like it or lump it, it's here and as far as partners are concerned I have said that too.'

Another important factor in experience of disability is the visibility of impairment: for those with hidden impairments, passing for normal is much easier. It is often a matter of personal choice as to whether to disclose possession of impairments such as diabetes, epilepsy, dyslexia. The sociologist Erving Goffman distinguishes 'discrediting' and 'discreditable' stigma, suggesting that in the former case there is a necessity of managing interaction, and in the latter case of managing information (Goffman, 1968). We would add that people with hidden impairments are sometimes less likely to 'come out' as disabled, and move to a positive acceptance of difference and a political identity, because it is easier to maintain a 'normal' identity.

Some respondents, who were more politically active, identified a group of disabled people who were actively involved in the disability world, but who had not 'come out' as disabled in a political sense, as Jazz describes:

'I call them able-bodied disabled people, people who work in the disability field [...] as [committee chairs], and 1 used to find this, that you have chairs who have been dignitaries who were disabled, quite severely disabled, and really played on that, but didn't understand disability politics. [...] They would say "Yes I am disabled" and they'd use all the benefits that you get from that, but they hadn't actually said "Well I am disabled" in a political sort of way, oh no, they didn't identify with other disabled people, they didn't want to be identified with other disabled people.'

To conclude this brief survey of issues around disability identity, it is critical to point out that, whether impairment is congenital or acquired, the real problems for disabled people are experiencing discrimination and unmet need and prejudice. Disability is a social identity, not consequence of physical changes.

Coming out

We were interested in what 'coming out' meant to disabled people. For Stuart, an activist, coming out was about redefining disability:

‘I think you can only come out when you first come into contact with an understanding that the difference you have causes you oppression, and that you are not the problem, it’s society, and that occurred at university, when I came into contact with the social model theory.’

For him, this was also about being a member of a group:

‘It’s a collective thing, it’s the fact that disabled people have collectively helped give each other confidence in themselves, and that you draw strength from other disabled people, you draw strength from the culture of being in the disability movement, you draw strength from being allowed to express yourself, both politically, through articles, through art, whatever’.

Jenny, also born disabled, talked about the shifts involved in coming out:

‘I had an identity that I was different, and that I was unique, I was special. It was only … I didn’t know what I was supposed to do with this, I sort of felt angry, and I was made to feel because I was angry that it was because of me, or problems that were in me. It was only when I moved down into south London and met other disabled people, and disabled people in another context other than in hospital or the medical world, when I actually met activists, definitely people who were much more politically aware, much more supportive, and much more sharing, that I began to realize that a lot of the anger I was feeling was not me, but was because of society. Therefore I began to sort of feel proud of saying I was a disabled woman, because I no longer felt ashamed, I no longer felt apologetic, it was OK that I was disabled’.

Zorah, who became disabled aged twenty-seven, described the process:

'Stage 1: worrying; stage 2: acceptance of impairment and political identification with disabled people as a group, and fighting for access, etc.; stage 3: getting totally fed up with (a) restrictions on my life because of crap access and (b) getting fucking knackered all the time.'

Having been a lesbian since age twenty, the notion of coming out was familiar to her:

'I seem to have come out several times -as a dyke, as a Jew, as physically disabled, and now as someone with mental health issues.

There were several points at which I came out as a crip -as I moved from being someone with a sudden mysterious medical condition to being someone with a long-term impairment. The first time I used a walking stick at a party given by disabled dykes was very scary -I thought they'd think I was faking. However they ended up being glad and accepted me into the community. Also, I guess I became "real wheelchair user" the first time I had to get four policemen to help me get to the toilet at a blockade of Parliament.'

This conversation with another disabled lesbian, Kit, traces some of the process:

TS: So you had an impairment, and then a number of years later you became disabled, you came out?
Kit: I got involved with the disabled movement.
TS: What, was that about coming out?
Kit: Yes, part of that, well, I felt angry, and I didn't know why, I thought I was the only disabled person in the whole wide world, and again, I never went to school with disabled people, I'd never met a disabled person, and I certainly didn't identify with disabled persons. [...] Well, I was shit scared, actually when I went to that first meeting, and I was sat in a room with disabled people, and I had never met disabled people, and lots of things went through my mind, like should I really be here, and am I a real disabled person, or am I an ill person, or is this about being defeated, actually taking identity. ..?
TS: About giving up?
Kit: Yes, and how is that going to be received, is it going to be received like. ..giving up, but I also felt so excited that I had actually found the discussion that was being had in this room, the anger that was being expressed, that's me, this is my home.

Having made the transition to a positive disability identity, and often having taken on a political approach, life becomes slightly easier for many people, although issues obviously remain: as Eddie told us, 'I know something now which I didn't know. I think deep down I'm an OK person. Physically, I still have problems with the idea that I'm attractive. '

Daniel had always thought his disability made him 'horrible', had not associated with disabled people, and had disbelieved the non-disabled people who loved and respected him: eventually, however, he had to shift his perspective:

'. ..realizing that this whole experience that I was feeling others had felt, and this was not just about me, but something bigger, something out there, because other people were experiencing the same thing. I think in four or five years my life has changed dramatically. I became involved with disabled people, and I wouldn't say that I love being impaired, but. ..it's never as absolute as that. ..I still go through times when I feel wrong, but I also feel times when I feel very right! And that's completely different from before.'

As well as the individual dimension of having come out as a disabled person, there is also a sense of membership of a wider culture, which is often important to those who are involved in the disability movement Eddie again:

'We have, as disabled people, our own history, we have our own music we even have our own sport, we have a whole different culture, and that culture is something to be proud of, because it's oppressed, our culture has been oppressed for so long, and we are fighting against that is different ways and I think we should be proud of that.'

To summarize, 'coming out' for our respondents involved redefinining disability as a political oppression; identifying collectively with other disabled people and with disability culture; overcoming the internalized oppression which was discussed in the previous chapter. It therefore has personal and psychological benefits, as well as social and political value.

Female identity

While disabled people in general face discrimination and marginalization, disabled women are particularly oppressed. American research by William Hanna and Betsy Rogovsky (1991) analysed social participation statistics to reveal that disabled women were less likely to be married, were educationally disadvantaged, and experienced employment and income disparity. These effects were more than a straightforward combination of the experience of women and the experience of disabled people, providing evidence that there is a qualitative difference for disabled women. In Britain, there is quantitative evidence that more women than men are disabled (Martin et al., 1988), and there is qualitative evidence that disabled women face social exclusion and prejudice (Morris, 1989; Lonsdale, 1990).

Sexist stereotypes of women reinforce prejudices about disability: Oliver argues 'there are strong links between the assumed passivity of disabled people and the assumed passivity of women' (1990: 72). In both cases, dependency, vulnerability, and frailty are the dominant associations in patriarchal culture. Therefore disabled women are represented, as Morris points out, in particularly negative and passive ways (Morris, 1991: 97). Two American women have written of the dichotomy between the ultra-negative and the ultra-saintly view of disabled women (Saxton and Howe, 1988: 105):

> Disabled women are typically regarded by the culture at two extremes: on the one hand, our lives are thought to be pitiful, full of pain, the result of senseless tragedy; on the other hand, we are seen as inspirational beings, nearly raised to sainthood by those who perceive our suffering with awe.

There were varying perspectives on the relationship between disability and gender identity amongst the women who talked to us, although most agreed that impairment did have an impact. Kirsten also felt that gender had an impact on experience of impairment:

'I think the experience of myself as a blind woman, and that of my male counterparts, are very different. Immediately there is a challenge because women are the copers in the world, and we are very good at it (certainly my blind women friends who are mothers experience this), yet there is that dichotomy of having to be the capable one yet living in a society where we are assumed not to be capable. Sexism of our society enables me not to have to do certain things, I can be more protected by able-bodied men in particular. They would see touching more difficult to do to a blind man.'

Paula talked about the impact of impairment on experience of gender:

'I think that as a woman, you're perceived to lose all of your roles. If you're a man and you're reasonably smart, then you can overcome it, you can get on with your life, but as a woman you always feel as if you are fitting into someone else's scheme of things, not that I ever did that particularly well! [...] People have said "It's such a shame, you're such a bonny lass", and you think "Would it be OK if I was stupid and ugly?" if you think all of a sudden they have taken away an element of what is me. I have suddenly become unacceptable as a wife or a mother and I probably couldn't fare too well as a hooker, so there you go: all three of them out of the window. And when I say that I am divorced people assume my husband left me, not the other way round.'

This de-gendering is experienced during adolescence by those who are born with impairment. Victoria is a woman with cerebral palsy quoted in an American collection (Bullard and Knight, 1981:28):

> I stuck with able-bodied kids that had never seen a kid in braces before. I wasn't being treated as a girl. This was very painful for me, because I hung around with a group of guys who were really my good friends. They treated me like one of the fellows, and I did not feel like one.

In our research, Jazz said:

'I think that disability is a breed on its own, neither masculine or feminine.'

Zorah also challenged existing stereotypes of femininity:

'As a woman I certainly do not fit into "feminine" role and have never wanted to and would rather be dead … as a dyke I probably fit into the stereotype of being a man-hating butch with hairy legs, and if they don't like it they can stuff it.'

Other women felt their impairments had damaged their womanness.
Beth wrote:

'I have always been proud of being a woman, I still am, but my condition has changed my image of myself. I succeeded in an area of work, and at a level which was largely dominated by men, but I feel that I achieved this without losing my femininity. I was confident that I was an attractive woman and could relate to others on my own terms. I still have confidence in my intellectual ability, but not in my body image. I no longer feel attractive to myself or others.'

Others also felt their experience of disability had influenced their experience of being a woman, as Veronica told us:

'Yes, I feel that as a disabled woman because of my disability it has made opportunities for relationships more difficult and different from those of able-bodied women because this is the way in which I am perceived by able-bodied people.'

Jazz felt her disability had liberated her from the expectations of her cultural background, and enabled her to be her own person:

'I'm Jordanian, and if I'd been born able-bodied in Jordan, I'd be married with several kids, and subjected to my husband, for me it's a good thing being disabled. […] I remember when I was out there, my grandmother - I'd never seen this woman before in my life, the first thing she said was "Do you have periods?" [...] Well, I think it's very funny, to be a woman in the Middle East is to have children, the two things go together, you are not considered a woman if you can't have kids, that's the crux of it.' !

Jenny's comments show how disability is not seen as compatible with being a woman in British society:

'I feel that if I was not disabled, then I would allow myself, and society would allow me, to be a woman, whatever that means. Because I am disabled you are encouraged to be pretty and childlike, but childlike is not being a woman. So being disabled affects whether people think of you as a woman, which therefore for me impacts on whether I think I am a woman.

The .responses. of the women in our research, then, partly reinforce existing theories about disabled women: 'Unlike the non-disabled woman, who has societally sanctioned roles as mother and wife (restrictive though they may be), the disabled woman has no adult roles. Neither mother nor wife nor worker shall she be' (Blackwell-Stratten et al., 1988: 307). However, it would be difficult to conclude that these women were victims: despite the oppression they experienced, the majority of the women we spoke to had a positive sense of self, and had developed alternative identities and lifestyles.

Masculinity

There is an assumption that disability and masculinity are conflicting identities, because of the contradictions of the two stereotypes. Jenny Morris suggests: 'The social definition of masculinity is inextricably bound with a celebration of strength, of perfect bodies. At the same time, to be masculine is not to be vulnerable. It is also linked to celebration of youth and of taking bodily functions for granted (Morris, 1991: 93). The idea that masculinity involves a denial and weakness, of emotions, and of frailty is very common in culture criticism. A typical theme in films about disabled people is of the man often a war veteran, coming to terms with loss of masculinity through impairment - and this is usually characterized or crystallized in the context of impotency or sexual incapacity. Thus The Men, Born on the Fourth of July, Waterdance all centre on the disabled man and his difficulties in adjusting. The messages here are about stereotyped man, heterosexuality, and stereotyped disabled people's dependence. Prevailing images of masculinity, and of disability, offer conflicting roles and identities. The disabled anthropologist Robert Murphy supported these assumptions: 'The sex lives of most paralysed men, however remain symbolic of a more general passivity and dependency that touches every aspect of their existence and is the antithesis of the main values of direction, activity, initiative and control' (Murphy, 1987: 83). Nigel, a gay man with learning difficulties, expresses this experience:

'I get mixed messages. As a disabled person I am told to be meek and mild, childlike. Yet as a man I am meant to be masterful, a leader, get angry.'

However, while the clash of stereotypes may lead to confusions, the reality for disabled men is more complicated and less straightforward than the simple divergence which is assumed.

Patrick, a gay man with visual impairment, did not conform to expected behaviour for boys and men, because of being disabled:

'So I suppose I grew up with the feeling of not being very physically strong and even now I feel like that. Walking down a dark street at night I don't like. ..if someone was to jump from the shadows and attack me, I don't feel like I could defend myself. Society doesn't expect you to be physically strong if you are disabled.'

Jeremy, another gay man, said his mother thought that his disability was the reason for his gayness:

'Because my disability means that most women are stronger than me, like when it comes to opening a train door, so I would like to think I am not as sexist as an able-bodied man is, because if, like, I couldn't open a bottle, I would get whoever was with me, a woman or male friend to do it. So the strength thing doesn't relate to me, most women are stronger than me. I never actually thought about the masculinity thing, it's never come into it, because I just assume that most people are stronger than me anyway. [...]

'It has taken ages just to think of myself as a man. I don't actually think of myself, because when you say a man, you think of someone who's strong, the usual stereotypes, but I'm not any of those, although I am male. Up until a few years ago, people used to think I was a woman, small hands, didn't have a beard, and my voice was quite. ..I presume it's quite feminine I don't know. ..I've never been into cross-dressing or drag or anything like that. [...] Whenever I've met other guys they've always seemed to assume that I would be the one who would be fucked. It's quite a surprise to them when I tell them that I don't want to be, and that I don't like it.'

Sometimes, young disabled men, because they are seen as unthreatening and asexual, may have closer relationships with women than their other heterosexual peers, perhaps replicating the relationship between gay men and straight women. However, in the case of disabled heterosexual men, this enhanced communication with the opposite sex also involves denial of their sexual potential, and can be undermining: for example, Eddie told us:

'I was always a good listener, and I was like a big brother figure for those girls who I fancied. When I fancied a girl, I wouldn't tell her. I was seen as a really good guy, you had a good laugh, I would always listen. Most women saw me as a big brother, rather than a boyfriend, and certainly safe.'

The assumption, mentioned by a number of male respondents, that because of their impairment disabled men are perceived as safe, is an example of biological reductionism. There is certainly evidence that disabled men are capable of violence and abuse towards women and children and other men. Paradoxically, despite the assumptions of women friends, for Eddie his working-class background meant that 'being a man' involved physical strength, and his impairment was an obstacle to expressing this aspect of masculinity:

'I was involved in a lot of fights outside school, although I would not fight a disabled person. A lot of people took the piss out of me, and my brothers had taught me from an early age about fighting. I was in a position where people would take the piss out of me and I would fight back. ..I gave people good hidings! It wasn't a problem that I was in a wheelchair, in fact it was an advantage. I couldn't do anything, and then they would come closer, and then I would smack them in. I would get myself into a position where I knew someone would attack me, and then I would hit them, and feel justified in hitting them. I had these problems at school, they thought my dad was abusing me, I would go in with a black eye and I had been fighting in the streets, and they couldn't accept a disabled person had been fighting.'

This quotation captures the difference between assumptions made about disabled men, and the reality of their lives. Another anecdote, from Michael shows how the respondent believed disabled men are occasionally treated in a analogous manner to women:

'Yes, because you know, if you go to a restaurant with somebody, it’s always the man's place to pay the bill and stuff like that, whereas I find if you're disabled it's not necessarily your place to pay the bill, because you're the poor little disabled person that presumably hasn't got much money. [...] I find it highly frustrating when I go in with another able bodied person, and they automatically present the bill to the able bodied person instead of me, and I have on occasions said "Actually I'm paying the bill", they have said "OOPS, sorry!" and got rather embarrassed.'

Zebedee echoes Michael's feelings:

'The general stereotype of a man is of a strong person, a person who is able, and can take command. Now because of the number of friends who actually accept that I am dominant and fairly able, I do tend take control in situations like that, but in a lot of society I am treated as this rather wimpish person who can't make their own decisions. Unfortunately this means that I am unable to put over to some people the fact that I am male.'

In our view, disabled masculinity is a different experience to that of non-disabled men, and the new literature that is developing on masculinity fails to address this. Disabled men do not automatically enjoy the power and privileges of non-disabled men, and cannot be assumed to have access to the same physical resources. Moreover, masculinity may be experienced negatively in a way which is rare for heterosexual non-disabled men. Eddie expressed this point:

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

Bob Connell's work explores the varieties of masculinities, moving away from an essentialist notion of 'natural' masculinity (Connell, I995). His more subtle and complex approach is open to the variations implicit in disabled masculinity, and influenced one of the few pieces of research into masculinity and disability. Americans Thomas Gerschick and Adam Miller (I995) investigated the clash between hegemonic masculinity and social perceptions of disability as weakness through interviews with ten disabled men. They found three dominant strategies employed: reformulation, which entailed men redefining masculinity according to their own terms; reliance, which entailed men internalizing traditional meanings of masculinity and attempting to continue to meet these expectations; and rejection, which was about creating alternative masculine identities and subcultures. Those who followed the second strategy encountered the most problems, owing to their inability to meet social standards of masculinity. Often this resulted in anger, frustration, and depression. The first group, through altering their ways of thinking, and adapting masculine ideals to their own lifestyle possibilities, achieved considerable success by departing from tradition. The third group went further in letting go of conventional gender identity and rejecting the ideology of masculinity: often this was linked to membership of the disability rights movement, with its alternative value system and support structures. The authors argue (Gerschick and Miller, 1995:202):

Thus, men with disabilities who rejected or renounced masculinity did so as a process of deviance disavowal. They realised it was societal conceptions of masculinity, rather than themselves, that were problematic. In doing so, they were able to create alternative gender practices.

Being sexual

In the introduction, we discussed the ways in which disabled people were defined as asexual. The assumptions made about disabled people are often a major bar to sexual expression. Disabled people face a considerable amount of curiosity and voyeurism as to their sexual lives Paula told us a relevant anecdote:

'This head waiter that I knew well, I could speak Italian and we got on reasonably well, and he came up to me and said "You can't, can you. ..? I said 'Can't what?" ...I knew what he meant, I thought, I'll drag that out a bit, and he said "Well, you can't have sex, can you?" and I said "Why ever not?" and he said "Well, you can't walk. ..", and I said "You walk while you're having sex? I haven't seen that in the Karma Sutra!'"

Beth, with the same impairment, was less positive about her sexuality:

'I am sure that other people see a wheelchair first, me second, and woman third, if at all. A close friend assumed that, for me, sex was a thing of the past. I think that this is a view that is shared by the majority. It may have little reality, but influences my self-image. The more disabled I get, the more my body becomes public property. It is no longer under my control. I must accept intimate help and often lack any privacy if my physical needs are to be met. I find it hard to switch roles from one who must accept the kind of help that I need, to one who is confident with personal relationships and still able to feel attractive.'

When asked about the different significance of disability and sexuality Veronica told us:

'Both are important, but it is much harder to assert my sexuality and show myself to be a person with sexual feelings, rights and a sexual identity rather than merely being a disabled person.'

Elizabeth had experienced disability very negatively:

'It means a very lonely life and little opportunity to have my work seen either. I became disabled in my early thirties. I have no idea what it means to others except a nuisance and a pest to friends, and others take advantage and exploit it -use me and steal my things and food. I feel quite highly sexed but have always had little opportunity to express it.'

Mark also experienced such barriers:

'Being disabled means no sex [...] my body does not belong to me. People look at you in a "different way".'

Often disabled young people are more dependent than non-disabled young people, and sometimes parents or professionals are over-protective, and may infantilize them. This is particularly the case with certain impairments. This may have implications for sexuality, because often treating people as if they were children involves denying the possibility of their being sexual, as with older people. Raymond, a Black People First worker, talked about the experience of people with learning difficulties:

'As an advocacy worker, I see a lot of instances in group homes where staff will not allow residents to express themselves sexually. Their needs are very often not respected, and it is often the same if the individual lives at home with parents. I have experienced a lot of over-protection, and a sense that parents are afraid to "let go" of their children sexually. This is often normal for most parents, but for parents of children with learning difficulties it seems to be a lot worse. Sometimes they will dress their adult children in "young" clothes as a way of denying their sexuality. They can also be very intrusive into the personal lives of their children.'

So often, it is the attitudes of others which undermine the sexuality of disabled people, not the consequences of impairment itself.

Imagery

Stereotypes of disabled people

This section continues from the previous discussion of the denial of disabled people's sexual identity: images and attitudes around disability are among the main problems faced by disabled people attempting to assert themselves as independent adults and positive sexual beings. The journal Disability Now reported the experiences of a disabled woman shopping for lingerie: the shop assistant first assumed that it was for her daughter, and, on being corrected, then recommended a range of warm thermal underwear with lace trimmings (September I~92: 22).

Beth's comments summarize the cultural attitudes to disabled people:

'One of the reasons that I have difficulty in accepting the label "disabled" is because the predominant images of people who fit that label have little to do with me. Negative images which focus on dependence, guilt, pity, and fear are perpetuated by the media, the work of many charities and adherence to the individual or medical model of disability. A typical disabled person is seen as having little control over his or her life, is dependent on others, has no rights and is not considered to be actively sexual, or have sexual desires or feelings.'

Most respondents were able immediately to highlight the dominant images of disability in contemporary culture: for example, a gay man with hidden impairment mentioned 'sad, pitiful, unable, super crip, unemployable, non sexual and many more'.

Nigel said:

'The images of disabled people are largely pathetic needy childlike people. But who benefits from this portrayal of disabled people? Who benefits from any poster campaign of pathetic disabled people?'

Images of disabled people are not always overtly negative. For example, there are stereotypes such as brave, plucky, etc. Patrick resented these reactions:

'Personally, if I ever had anybody writing a news article about me, putting down the words brave or courageous, they would be told to forget it, and told not to bother writing it if they're going to come out with that kind of rubbish.'

Euphemisms for disability, such as 'physically challenged' or 'differently abled', got short shrift from Ronan:

'Bloody daft! "Physically challenged", what does that mean, I can't get up in the morning when I've got a hangover? We are all "differently abled” […] I can't do DIY [just] because I've got a bloody colostomy,

One of the main problems with disabling imagery and disabling attitudes was that they lumped all disabled people together and treated them the same. Binnie highlighted this:

'Often I feel that hearing people, when they find deaf people do something wrong, for example, they are lazy or whatever, they treat all deaf people then the same way. Now that's not true, every deaf person is different, they are individuals, they are just like hearing people.'

Deaf respondents felt that deaf people were treated as being incompetent by hearing people Phillipe:

'So they treat deaf people as a lower common denominator, lower-class citizen, they push them off to one side, as stupid and thick and dumb, and again linked to dumb because of the old traditional way of saying deaf and dumb.'

These images of disability impact on disabled people's sexuality. Julie said:

'These images are a sexual turn-off and a complete blow to the confidence.'

Kirsten told us that in her experience disabled people were seen as:

'Very unsexy, but also as slightly monstrous and very perverted. Which always makes it a bit of a challenge being a lesbian actually, because they just think you are being utterly perverse and perverted. The image of a disabled person is not a sexual being, it's not someone attractive and beautiful.'

This quotation captures the paradox that disabled people are variously seen as asexual, but also as! perverse, hyper-sexual, and deviant.

Stereotypes of sex and beauty

We live in a society which has very strong and very limited notions of acceptable physical appearance, which are oppressive to a whole range of people. The media, the fashion industry, and popular culture in general reinforce stereotypes and promote superficial and skin-deep ideas about what is attractive. These often reinforce a view that people are inadequate and unlovable. Our respondents found it easy summarize ideas of acceptable appearance and the body beautiful, even while many actively disowned them. Jenny said:

'It means being a size I2, it means having long blonde hair, blue eyes, it means being the perfect race, all those images. It means conforming, it means tons of time being spent just so you look good, for somebody or people. Body beautiful is very powerful, it's one of those phrases, a bit like physical correctness, what does it actually mean? It's about changing your body to meet somebody else's view of how it should be.'

As Kirsten said:

'We are living in a world that kind of, like, respects symmetry, respects thinness, respects smoothness, and sort of, smooth movement and stuff like that, when we can't do it in the same way, it's very difficult.'

Notions of sexual attractiveness, appropriate physique, and norms of beauty and appearance affect different groups in different ways. For example, women are more likely to be judged on their physical appearance than men. This means that disabled women may suffer more as a result of their divergence from bodily norms. Janice, quoted by Wendy Chapkis (I986: I6I), says:

> I've often felt that disabled women who want to relate to men are at a terrible disadvantage because men do buy into the good looks syndrome. Women don't so much. I don't choose a man for his looks. A disabled man has a much better chance in this world of finding partners.

However, the gay community is also notorious for its 'body fascism', placing a premium on youth, strength, and looks. Nigel, who is gay and has a physical impairment as well as learning difficulties, feels:

'The gay community is into the body beautiful. Gay men are looking for the nearest thing to the body beautiful in a man. If disability is considered at jail, it is in a stereotypical way and if you don't fit that stereotype, forget it. Some gay men are into amputees, or young men who have short stature: if your disability is different to these "popular" ones then no one is interested. Also if your disability is not HIV-related, you lose essential Brownie points.'

Lesbians reported to us that the lesbian community had moved away from the 1970s stereotype and embraced the cult of the body, in terms of looking sexy, but also in terms of favoured leisure pursuits such as walking, line-dancing, and going to the gym. Kit pointed this out:

'Like you notice much more at women's discos that there is a particular dress code which used to be "scruffs" and is now sort of, the most flesh you can reveal the better'

Kath had experienced this change too:

'There has been such a radical change in the last ten years, it's so different because there isn't really a women's movement as such, we don't even have a newsletter [...] it's all about how you look, how you talk, it's almost crude, it’s almost vulgar, it's all about culture, you must be thin, you must wear leather. [...]

'Having said that, the look, the image of lesbian has been traditionally so denigrated that in a sense it is very positive [...] it's a reaction to the dungarees, the short hair cut, tattier than thou. [In the I970s] You weren't allowed to iron your shirts. No wonder gay men and lesbians don't understand each other!'

Another lesbian respondent, Julie, sums up the ambivalence many have towards notions of beauty:

'There is a whole culture of body fascism in our society because we're indoctrinated with a "youth culture" and "survival of the fittest" mentality. I want to fight it all the time, but I find myself still getting turned on by youthful images of oiled bodies rolling in the sun and surf in wet T-shirts.'

Unfortunately, it is also important to report that the disabled community is not immune from physical prejudice: in Wendy Chapkis's book on women and body image, Ann, who has restricted growth, suggests (Chapkis, I986: II9):

> There is a real hierarchy of what is acceptable appearance within the disabled community: what is beautiful, what is ugly. At the top is someone who sits in a wheelchair but looks perfect. I have a friend who has cerebral palsy; she always says cerebral palsy is the dregs. They drool and have a speech impairment, movement problems, that kind of thing. On the high end of the scale is the person with a polio disability because physically they look okay. It's something we have to work on.

In segregated contexts such as special schools, a pecking order of impairment often exists. Daniel, who was very sexually active at his boarding school, recorded that

'The most desirable boys were haemophiliac, as they were closest to being non-disabled, were almost god-like, and the least desirable were those with muscular dystrophy, and I was somewhere in the middle.'

Comments like this show that disabled people themselves often discriminate on physical grounds. Many disabled people avoid associating with other disabled people, others avoid having relationships with them. Disabled people who talked to us said that they themselves were guilty of such attitudes: for example, Patrick said

‘ ...it has affected me unfortunately, no points for political correctness when it comes to dating men. In the past I've nearly always ended up going out with so-called non-disabled people, I've gone out with a few disabled people as well, but just very few. I would say that probably because of this body beautiful image, it gets to us all, like I still tend to go for a nice good-looking six foot two, not necessarily six foot two, but just nice and good looking, who's not bald.'

Jo held similar attitudes:

'I have this annoying bias toward thin people. I fancy my cousin [...] I find it difficult thinking about disabled people having sex. It's all right for some (the more non-disabled looking ones) but I haven't got my head around all disabled people having sex yet. I know this is right-off, but this is shifting and the idea is becoming more acceptable over time. [...] It's the idea of legs not working and seeing them with no clothes on. ..I'm now OK about myself. ..I think I'll be all right, but the idea of other disabled puts me off.'

Sometimes it seems that people's feelings about themselves influence this desire to avoid contact with other disabled people: those who had accepted their own condition were likely to be happier to associate with others in the same situation.

It is commonly accepted that one of the keys to feeling attractive and being desirable is being happy with oneself and one's body. That is, rather than objective criteria of appearance, it is the way one feels about oneself which makes one appear sexy or beautiful. Daniel, who has had problems with his physicality, discussed this issue:

'My friends still tease me about being involved largely with non-disabled men [...] it is partly the scene, it is also to do with the fact that disabled men feel the same way as I do, and one of the desirable things I find in men is that they feel OK within themselves and I find (although I have come a long way myself) that most disabled men (although I haven't done a survey) don't feel good about their bodies. So when I look at men, I'm attracted to those who are comfortable with their bodies and largely they are non-disabled men.'

Zebedee felt it was up to disabled people to present themselves well:

'I do see among other disabled people that many don't actually make any effort to make themselves I presentable, and unfortunately this leads to them being shunned by other people. This is sad, and it's something that blind people in particular need to be aware of and need to take account of, in fact there really ought to be a lot more emphasis put on this in schools and the like. It really is not acceptable for somebody to jump up and down on their feet as they are talking, or rock backwards and forwards, this is something that we call blindisms, which is something that sighted [people] certainly find very irritating.'

Other disabled people would say the onus lies on society to be more open and tolerant of difference.

Disabled people and self-image

Nancy Mairs has written about her experiences of 'being a cripple', and about her body (I992: 63):

> My shoulders droop and tiny pelvis thrusts forward as I try to balance myself upright, throwing my frame into a bony S. As a result of contractures, one shoulder is higher than the other and I carry one arm bent in front of me, the fingers curled into a claw. My left arm and leg have wasted into pipe-stems, and I

> try always to keep them covered. When I think about how my body must look to others, especially to men, to whom I have been trained to display myself, I feel ludicrous, even loathsome.

Jane Elder Bogle and Susan L. Shaul have analysed some of the problems of body image for disabled women. First, they highlight the negative reactions from others about the body (Bogle and Shaul, I98I: 92):

> There's no positive value in the outside world, on having a disabled body, no matter how well it's functioning, or how unique or how beautiful it might be. It's very easy to consider one's body as the enemy when you're getting all negative input from the outside world. Your body can be the source of a lot of pain, embarrassment, trouble, guilt, expense, and for some people, isolation with long periods of hospitalization and separation from the people that they love.

Second, they mention the lack of bodily control experienced by many people with impairment. Our respondents talked about issues such as incontinence, managing colostomies, infantile and uncontrolled behaviour. Many disabled people end up by disassociating from their body -not owning it because it causes trouble, or because someone else cares for it. Sometimes, parents had inculcated negative attitudes to the body.

Another factor for some disabled people is the reliance on appliances and aids. Bogle and Shaul suggest (I98I: 93):

> Most of us need to rely on some hardware to get around, such as braces, crutches, wheelchairs, and catheters. They can be very difficult to incorporate into our concept of being sexually desirable people. Generally, they are metal; they're hard, cold, angular, and usually ugly. It's difficult to integrate that into the sense of being warm, squeezable, and lovable.

One of the women in Lonsdale's survey had exchanged crutch and callipers for a wheelchair: 'She felt they could cope better with a woman perceived to be more dependent and "helpless" in a wheelchair than with a woman perceived to be clumsy or "ugly" and possibly more assertive in calipers' (Lonsdale, I990: 4).

Finally, there is the experience of partner reaction -in some cases, bodily changes become the reason for rejection. Hence disabled people remain isolated and do not take risks.

In our experience, these features of self-image are not restricted solely to disabled women: men may also experience similar problems with their body and their feelings about their body, as Eddie points out:

'There is this thing which I believed for a while, that I was ugly, but it had nothing to do with my facial features, it was because I was disabled. [...] But some people can feel kind of OK about themselves, well I find it very hard to do, I feel like this idea of good looking would be quite handsome, not overweight, muscular.'

Eddie discussed his difficulties with looking at himself in a mirror. This is often mentioned by disabled people. For example, Ann, a woman with restricted growth who writes in Chapkis's collection, says: 'It wasn't until about a year ago that I really knew what I looked like. If I ever looked at myself in a full-length mirror (which I never did), I would get freaked out. I couldn't understand how people could relate normally to someone who looked like that' (Chapkis, I986: 20). Experience of disabled people perhaps echoes that of women in some senses, in terms of failure to match up to: a social norm or expectation. Eddie made the comparison:

'I see a shirt on some people, some youngster's wearing it, and I think, wow, I want that shirt, and I wear it and I think "God you look awful". Women have that, they see a beautiful dress and they put it on and they think "God I'm ugly".'

For disabled women, however, it is a combination of failing to meet two sets of expectations (Lonsdale, I990: 4):

> Someone who users calipers or a wheelchair cannot walk on stiletto heels; someone with facial scarring or disfigurement cannot look like the advertisements for make-up; and someone with scoliosis or who is born without arms or legs cannot approximate Marilyn Monroe.

While the situation for disabled men may be more problematic than that for non-disabled men, the situation for disabled women seems likely to be worse, because physical appearance is a more significant attribute for women than for men in a sexist society. As Wendy Chapkis argues (I986: I5):

> Man believes he survives through his enduring achievements. Woman is her mortal body. A man's relationship to his body, then, appears to be less fraught with tension than a woman's. The male mind can afford to be a more lenient master over the body, indulging in the appetites of the flesh. A man may sweat, scar and age; none of these indications of physicality and mortality are seen to define the male self.

Fighting the stereotype

Changing body image and increasing self-acceptance is not impossible for disabled people, but it takes time. For example, it may involve rejection of social judgements by others, and replacement by internally based body image. This might include valuing compensatory competencies (strong arms and shoulders and chests) -and using the body to one's own advantage. Often processes such as assertiveness training, positive feedback, learning to accept compliments are involved. Alternatively, many people have rejected stereotypical concepts of beauty, perhaps influenced by feminist ideas. Brenda told us:

'I went through issues about the body beautiful in the women's movement of the seventies and, overcame any hang-ups about body image. I no longer care what other people think.'

Many disabled people were well aware that they did not fit the stereotypes of masculinity or femininity, and were quite realistic and accepting about their appearance. Patrick told us:

'I'm a little short fat fellow with a big smile on his face and I don't look like a gay man, apparently, you know.'

Realism about his appearance was important to David, who has haemophilia, HIV and scoliosis:

'My disabilities are (mostly) visible: I limp, I have scoliosis, I'm very thin. I don't know to what extent the combination of these things puts people off, but it certainly doesn't help, and I've got rather fed up with people telling me it's all a question of body image. (A - more honest - friend of mine said to me once that nobody was going to want to go to bed with me for my body, but they might for other reasons -as indeed he has.)'

Many of the people who contributed to this research had developed very positive self-images, and strategies for feeling good about themselves and looking sexy. Sara said:

'I dress however I want, in leather, rubber, casual, to suit my mood. People are often shocked, it's unexpected. I also deny help, if I can manage, upsetting people’s ideas of how I should be. I keep my Independence and power.'

Penny told us about liberating experiences during the I970s Punk/New Wave explosion:

'A time when you could be anything and no one gave a shit! My sexuality bloomed with a vengeance. I dressed a bit like Madonna before her time: fetish gear with a punk edge was what I was most into. I would (and still do) wear the shortest black mini skirts I could find to shock people into staring at me. I still have an "attitude" about this -if some asshole objects to how my so-called "arthritic" legs look, they can damn well not look. I've just turned thirty-five and intend to grow old very disgracefully! During my punk years however, I did fall into the trap of trying too hard, becoming a caricature of female sexuality in order to make the men I fancied see beyond the wheelchair and crutches.'

Several respondents echoed the last point. Sometimes it seemed that, in order to be seen as viable or as sexual, or in order to manage interaction, exaggerated behaviour or appearance was called for. Paula, for example, when asked how she projected herself, replied:

‘Somebody who is probably slightly OTT. I have often said to people that I probably seem a little bit off the wall to others, but I have to speak to people before they make assumptions about me. […] I think that when you’re a disabled woman then you have to project at least an image of being self-assured, otherwise people will walk on you’.

Jenny spoke explicitly about the tension between rejecting the stereotype of how disabled people should look, and reinforcing the tension of how women should look:

'I have got very overt, very colourful, then at times felt like I am a neon light flashing on and off, but then I do get positive messages from everybody else saying "Gosh you look good in that". Conversely, once they've said I look good, I think, that's not something I want to wear, because they say I look good, therefore I'm conforming, and I'm doing what they think I should do.

Disabled people may have different views of what constitutes beauty.

Sara again:

'To me it means a totally self-directed person, happy with their inner and outer self, comfortable to be totally themselves. This is what I admire in others. I think this is not so for everyone. People see disabled people as deformed, not right, or broken or inferior, or second-best, damaged goods, etc. Where most people look for the normal, safe body, I admire the beauty in difference.'

Others asserted their individuality and rejected the norm. Zorah:

'I don't know if I project anything or if I just bulldoze my way through, and if women like me, they like me, and if they don't, they don't. I would like to dress better, but as a fat crip on a low income with little dress sense it ain't easy. I would like to come across as competent and efficient at what I do, and creative and talented, more than e.g. "sexy" or "beautiful".'

Many people tried to project images of themselves as intelligent, or in control. Jenny again:

'I try to project the image of being in control, of being assertive, of knowing where I'm going.'

Kirsten said

'My image is strong and in command, which is the thing that frightens everybody, you see. [...] I am fairly commanding in many ways, and also as a big woman there is a stereotype of bossiness. [...] People think I am really odd because I am really conscious of what I wear all the time. Certainly if I am in a work situation where I have got to go and do something that I am frightened of, then I put a skirt on, which is quite shocking, people kind of die of horror when they see my ankles you know! I will deliberately, for something difficult, dress up in a particular way, because it is part of my image of needing to be in control, because being blind you are not seen as being in control.'

Some disabled people we spoke to experienced continual changes in their relationship with their body, resulting from degenerative impairments such as muscular dystrophy. Stuart told us:

'Personally I am not ashamed of my body, I have adjusted to the fact that I am different. I think it's interesting to deal with the psychology of your body, because when your body is constantly changing -particularly when it deteriorates -what you find is that what you need, in the way you do things, is constantly changing. [...] I think that's where the social model's helped me to accept my difference, to give me pride in what I am as a disabled man, and I accept that my body has given me access to a whole set of experiences, whether negative or positive, which made me different, which gave me a different outlook, a different awareness of life, which is something positive which I can give.'

He also discussed the close relationship between bodily experiences and social identity. Prior to coming out as disabled he had a negative self-image, but subsequently he! took more care of himself:

Stuart: When I was a teenager I used to be affected a lot by chest infections, but since I came' out of university, since I began to gain some control of my life and began to look at routines, and began to relax more, and eat better, and! to take my time with life, my health just improved. I haven't had a bad chest infection for about seven years now.
TS: So when you took on a different social identity, of being a valid human being, your life improved?
Stuart: Yes, because my psychological health improved, because there is a close correlation between my impairment. ..there is a close correlation to your mental health and your physical health. Usually if I go through a bad period, when my mental health is very poor, I know that if I go through that period for say ten days to two weeks, there generally follows a bad illness. There is a very, very close correlation.

Looking after the physical body was an important part of feeling good about themselves for many respondents, especially those who had chronic illness: Ronan said:

'I know I'm never going to look like one of the people on calendars or anything, so I just look after my body so I feel good about it, and what I'm really pleased about in the last week or so is that I can have a bath again for the first time in months, having radiotherapy I couldn't have a bath, couldn't sit in a bath with soap, and now I do, put lots of hot water in, I unplug the chemotherapy, and put Raspberry Ripple bubble bath in, and just lie there for half an hour, soak, and my body feels beautiful when I have treated myself like that.'

David had advice for others starting out with an impairment:

'Try and see your body as a source of pleasure -it's the only one you've got. If you think that, say, putting on muscle or losing fat would make you feel more confident, give it a try.'

Impairment affects body image in other ways for other disabled people. For example, because of his visual impairment, Patrick hates going shopping: he feels pressure, as a gay man, to look fashionable, but takes someone with him to help him select clothes. Users of manual wheelchairs often develop powerful upper body muscle. Some people, especially men, may welcome this compensatory development. Some women we spoke to were less enthusiastic about having a 'butch' physique. Paul said:

'I think the fact that I have arms like Arnold Schwarzenegger is probably not one of my plus points. [...] I have to be careful about some things that I wear. I rarely wear clothes now that are off the shoulder, because I look like Mr Motivator.

Other women had also developed strategies. to minimize their difference, although sometimes ended up frustrated at the limitations their bodies presented: Beth wrote:

'The statement I make through my appearance is one which minimizes disability [...] I use clothes to cover any sign that my body has changed and to say that I am a person who cares about her appearance. I have difficulty finding clothes which are possible to wear in a wheelchair and resent the fact that I am constrained by my physical condition. I cannot look the way I want to.'

Just as people's bodies changed with increasing impairment, so the experience of disability led to changes in their ideas about beauty, as Beth told us:

'My own image of the "body beautiful" is slowly changing, although my own body certainly does not feel beautiful to me. I find bodies attractive, both sexually and aesthetically, and my ideas about what is attractive have been shaped by the symmetrical, slim but gently curved, healthy, well-cared-for figures which dominate the media and are prominently displayed as being the way to "look good". Perhaps one of the most important factors in creating the image is that associated with health. Part of my process of self-development is the very gradual awareness that beauty reflects an inward state not an outward appearance.'

Despite the provisos we have made, most of our respondents had succeeded in rejecting dominant images of the body beautiful, and had succeeded in developing a personal style. This may be to do with the fact that our sample is skewed towards more politicized and more urban disabled people. However, it suggests that, contrary to popular belief, disabled people are capable of healthy and positive self-image. Here are a series of comments by a middle-aged gay man with hidden impairment:

'I am me, and do not want to fit into someone else's idea of me ...I feel good about myself. ..The idea of the Body Beautiful is very dangerous ...I don't try to project an image, I project myself.'

Paula is involved in a feminist disability arts group, who perform a sketch mocking cosmetic surgery and ideals of beauty:

'What we are actually saying, is that what people often outwardly perceive is rather vacuous. We say that we are beautiful, we are sexy, we don't need to be Playmates, what we do need to recognize is that we feel that we are beautiful in ourselves, and we don't need to have some person to reconstruct us, surgically or otherwise.'

James Partridge was disfigured as a result of being severely burned, going on to found the Changing Faces charity which supports others in his situation. He was quoted in an article in The Observer newspaper (II February I996), and his comments would apply to many of the people we spoke to: 'I am never going to conform to society's requirements and I'm thrilled because I am blissfully released from all that crap. That's the liberation of disfigurement.'

Conclusion

In the previous chapter, we discussed the internalized oppression, which often creates an obstacle to disabled people's emotional well-being. In this chapter, we have shown that disabled people have the potential to develop a positive self-identity, rejecting a 'medical tragedy' view of disability, and celebrating disability pride. For many people, the key this is political understanding -much as the women's prioritized 'consciousness raising' -and collective' Sociologically, the importance of our research is in challenging notions of 'normality', and demonstrating that individuals impairment can create their own identity around difference. Further, have highlighted some of the complexities of gender identity, which ~ implications not just for understanding disability but for understanding masculinity and femininity in general.

Julie

In thinking about my identity and sexuality, I've decided that my entire view of the world stems from my and society's relationship with my vagina. My whole identity has been formed around my wounded understanding of myself as a woman in this society. I know that for the majority of men in this sexist culture, I am simply a seed depositary or seminal spittoon. I have been socialized as 'female' within a rape culture. That may sound extreme, but I have been raised to be looked at, to strive to belong to the in-group of successful females of 'the body beautiful', viewed and assessed in much the same manner as breed cattle. All women living in male-dominated cultures exist in an exploitative framework. The boundaries of our lives are dictated by the particular society in which we are raised, ours is determinedly capitalist. So while we live in a culture hell-bent on productivity and the survival of the fittest, disabled women, old women, and those of us who don't fit the current image of the cutie are readily discarded. How many disabled women do you see draped over the bonnet of a new Ford Fiesta to boost sales? How many old women do you meet flogging cosmetics on the front cover of Elle magazine?

Me? I'm a Mad woman, diagnosed, labelled and 'treated'. I don't fit, you see. I spit like a cat, fight with fury, and damn well refuse to. Madwomen are the ultimate threat to men in that we are regarded as unpredictable, out of control, and generally out of order. So the bastions of social control, our psychiatrists, psychologists, and the like, are elected to keep us in order via shock treatments, behaviour modification, cognitive therapy and chemical coshes. I've been through the latter three, but mercifully have been spared the electro-brain torture. ..so far. In considering the effects of any 'disability' on my sexuality, I need to acknowledge how this society removes power and disables those defined as mad. I want to look at how that affects me, at every level. The other issue I want to examine is how my 'treatment' has and does affect my sexuality.

In trying to understand who or what moulded my identity, I need to look at the context in which my parents lived and reared us -the three surviving children of their five. My father comes from an Irish Catholic family: his mother was a Weir from Ballyhack, his father a MacNamara from Arthurstown. They followed the McAlpine's building sites throughout England and Wales, as did most itinerant labourers, working wherever they could. His mother left their father, who was an alcoholic, and reared six children single-handed. It did not leave her sympathetic or affectionate in any way towards her children.

My mother comes from a huge Merseyside family of which there are six surviving sisters and three brothers. There were at least three fathers along the way, but the man I remember as 'Grandad' was a lovely man from the West Highlands of Scotland, Tony Minto. My mother was not baptized, but attended the local chapel as a child and believed herself to be a Protestant, until harangued by my father's home-brewed Catholicism to such a degree that she became an atheist.

I have two sisters. My older sister has spina bifida (and undivided attention), two fingers up at the world and three forbidden children. My younger sister has chronic colitis and dietary disorders, that could well result from the varying medications she receives via the mental health system. There were two more children who did not survive: the first child had severe spina bifida and died at birth, the third (just after me) was a cot death.

I will not enter into debates about the causes of mental distress, i.e. the nature versus nurture debate, is it physical or social in origin? How does that help me, or anyone else in distress? I have been involved in the mental health system, as a recipient of the helping services, and as a provider, since I979. I had a complete identity crisis at the age of nineteen, I turned to drugs, became suicidally depressed, and developed a paranoia about eating, eating in public in particular.

I was treated in a variety of mental health clinics and communities, swiftly passed from one professional to the next, until finally I was offered psychotherapy. I stayed in therapy for a year and a half. In the first clinic, with a Dr Fitzpatrick, I was told I was having an adolescent crisis, I needed to 'find my feet'. I was offered Tenuate Dospan (the nearest thing on the student market to Speed). I became hooked. Let me tell you, my feet moved very swiftly on this stuff. It works! Then I swung from depression to elation, manipulated by the drugs and the professionals 'trying to help'. My eating disorder got so out of hand, I could no longer hold food down, enter a cafe or restaurant. I became completely phobic about putting anything in my mouth. At that stage, nobody had suggested the links between food and sex, the symbolic meaning of food in the mouth, or my fears surrounding this. I sank further down the spiral bf drugs and depression until I attempted suicide on a massive overdose of LSD. I did not die. It changed my world. But that's another story.

In treatment, I was told that I was 'suffering from a homosexual retreat'. Quite what this means is anybody's guess, but I assumed they were using heterosexuality as the most desirable goal for my mental health. Wherever that retreat was, they were not going to sign me up. I was transferred to St Anne's hospital, the fourth move within two years. I was offered a psychologist to work with, somebody who would help me come to terms with myself. Within the relationship between us, I was to become a whole human being. This involved me falling in love with her to such a degree that I would have done anything to get attention from her. She said I 'looked a bit butch' and I'd 'probably suit a dress if only I'd try', so I turned up in a dress, hoping she'd roll in my arms pronto. 'Seeee, you do suit a dress. ..' (positive reinforcement of desired behaviour. ..) bringing the prodigal daughter back to the fold. The litmus paper, the yardstick for 'normality', was always measured against heterosexuality, and, usually, that of mating with the 'normal' male. All that I could read from this was that my desires for women, for people of the same sex, were odd, not normal, to be corrected, or just plain 'sick'. I rolled over, played dead, wore frocks, strutted my stuff and she still didn't love me in the way I loved her. ..so I moved on. The best line of the whole 'treatment' was her comment after asking me to describe a particular sexu4f encounter with a woman: 'See, you're no more lesbian than I am! ..I. that's not real sex, is it?' Looking back, I think she was probably persuadable.

The treatment I have received within the services has undoubtedly made its impact on my sexuality. I50mg of Prothaiden or Dothiepin daily causes every orifice I to dry up, never mind the dry mouth highlighted as its main 'side effect'. Some mornings it takes me a long while to emerge from the fog, and to be present in the world, so pre- breakfast sex is usually off the agenda. That's my main complaint about medication, but it's restored my sleep patterns, so it's roundabouts and swings really. The insidious nature of 'cognitive therapy' and other talking treatments leaves any vulnerable human being open to being brainwashed with an entirely new set of values and ways of thinking. That can be a lifesaver if somebody is obsessed with suicidal thoughts, or it can be a very damaging experience of internalizing experience, of internalizing more guilt and pain about sexual preference. This is because the premise from which most talking treatments are delivered is a heterosexual, able-bodied, WASP perspective. And I just don't fit that mould.

We're all raised in a heterosexual culture, to assume our positions in the scheme of things once we reach puberty. I just never took to the missionary position. I do like sex. It's just not the same with men. I have tried a few, all shapes and colours and sizes. ..but there's something missing. 'Breasts!' my shrink once said. ..but I'm not so sure, you see I am a 36D, which leaves very little air space for anyone else's at all. .. and I'm not sure about this 'body beautiful' culture we're all wrapped up in, but I do prefer bottoms. In fact, give me a good sized Mediterranean bottom any day.

I spend at least half the waking day thinking about it ...how to enact desires, fantasies, dreams and explorations. On a hot summer's day once I met a woman at a bus stop down here in London, and after a short preamble we had a very frank discussion about sex. She admitted to thinking about sex most of her spare time. That decided me that the rest of the world was probably doing the same. We just act upon it in differing ways.