

CHAPTER 11 (in 'Doing Disability Research' edited by Colin Barnes and Geof Mercer. Leeds, The Disability Press, pp. 177-189)

## Researching Disabled Sexuality

Tom Shakespeare

In 1996, two years after we commenced the research, Cassell published *The Sexual Politics of Disability: Untold Desires*. For Dominic Davies, Kath Gillespie-Sells and myself it was the end of a hard slog, a real moment of pride, but also an occasion for trepidation: what would other people think? How would the disability movement react? What difference would our book make? Had we done the right thing?

Researching and writing is largely under the authors' control. Of course, it is true that unexpected developments or problems may shape the development of the process, there is room for disagreement among collaborators, and books rarely end up exactly as they were intended. However, we exercised choice and control over the project, in negotiation with Cassell, which was relinquished once the book emerged on the market. At that stage, we could only wait and worry.

Post-structuralist writers have identified what they call 'the death of the author'. By this is meant the openness of a text to multiple interpretations. While the writers may have specific ambitions and intentions, once the book is in the public domain, others are free to read into it their own values and feelings, and to use the arguments and evidence it provides to promote ends which may be contrary to the authors' intentions. There is no way around this danger. For example, free market libertarians on the Right have adopted the anti-institutional emphasis of the disability movement to argue that day centres and other provision should be closed down. A progressive demand for autonomy and integration is converted into cuts in public services and rolling back of the state.

Nothing this extreme may result from our book on disabled sexuality. However, unscrupulous readers might find the description of disabled sex titillating: we felt it was very important to capture the creativity and energy of disabled people's sexual expression, but doing so runs the risk of supplying non-disabled voyeurs with material for erotic fantasies (not

a usual danger of academic writing). More importantly, perhaps, we might have mis-represented disabled people's experiences or desires, or distorted the evidence to provide an account which is unduly negative or positive.

It is unusual to be given the opportunity to reflect on the research process, to justify our work, and to correct any misapprehensions which have arisen. The reflexive discussion which follows is representative only of my views: my colleagues have not participated in writing this chapter. It has been difficult to avoid sounding either too defensive and apologetic, or too self-congratulatory. The important judgements about the work are those of other disabled people.

### WHY DID WE WRITE IT?

There are cynical answers to this question, which would be inaccurate, but cannot entirely be discounted. These include: personal ambition; desire for financial gain; voyeurism; academic credibility; opportunism. The altruistic answers might include: political commitment; perceived need; intellectual curiosity; professional development. The truth lies somewhere between these positions, and includes a considerable degree of pragmatism.

The original idea was Dominic's: we were to collaborate on a collection of accounts by lesbian and gay disabled people. Kath Gillespie-Sells was invited to join the team to bring a feminist and lesbian perspective. We shared a common commitment to sexual liberation and empowerment in general and to lesbian and gay rights in particular. When I made contact with Cassell, who publishes widely in this field, the commissioning editor steered us towards a more general book about the sexual politics of disability as a whole. This was a daunting prospect. Rapidly we moved away from a collection of essays on aspects of the issue, towards a book based on personal accounts, which we would gather from friends and strangers in the disabled community.

For me, there were various subsidiary intellectual reasons, with personal and political dimensions. My own concerns and politics focus as much on sexuality as on disability, and I have always worked in areas which are of direct interest to me and relevance to my life. A book which looked at identity, sexuality, relationships and parenting was of great interest to me, and also offered a chance to put my previous intellectual work on disability theory into practice. Moreover, having been trained as

a sociologist at the University of Cambridge, my work had largely been within social theory, which I increasingly felt was unhelpful and largely irrelevant to ordinary life. Inspired by the Chicago School, by Erving Goffman, and by feminist research, I wanted to do some 'proper sociology', by which I meant interviewing real people about their lives, and creating new knowledge, rather than criticising or recycling other people's work.

As we argue in the book, disabled people have usually been degendered and regarded as asexual, and we felt that the literature on disability had an absence around sexuality. There are various dimensions to this. Traditional literature on disability has been discredited by the emergence of the disability movement and the disability studies perspective, which is based on the social model and a disability equality approach rather than a medical tragedy assumption. While there are books which discuss disability and sexuality, they fall within the limitations of the traditional literature (Shakespeare et al, 1996: 1).

However, there was no existing book which effectively dealt with sexuality within the disability studies literature either. Key texts (e.g. Oliver, 1990) hardly mentioned the issue at all, and even feminist work (e.g. Morris, 1991) skirted round the issues. Although other accounts (e.g. Morris, 1989; Oliver, 1983; Hunt, 1966) do mention sexuality, there was still no book specifically and exclusively discussing the issues, drawing on qualitative research with disabled people. In general, with the exception of the feminist literature on disabled women, there has been little emphasis within disability studies on the realm of identity, personal experience, and private life. For us, the personal is political, and while we understood that the priority had been to explore structural relations and social barriers in the public spheres of life, we felt it was high time to redress the balance.

I have a suspicion that the disability community has had a reluctance to explore sexuality. Milton Diamond discusses the way that families and agencies avoid the issue, in terms which may be relevant to the disability movement itself:

'While they recognise that these are valid issues, they generally wish the sexual concerns to be ignored; they want them to sort of 'go away", since they are ill at ease dealing with them, and don't really know how to handle the issues' (Diamond, 1984: 210).

The American writer Ann Finger, argues that the disability rights movement has not put sexual rights at the forefront of its agenda:

'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about -and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction' (Finger, 1992: 9).

It was our experience that disabled people -like everyone else -often summed up their life ambitions in terms of 'a job, a partner, and a family'. We felt that the disability movement had made an effective challenge on the first issue, but not on the rest. British disabled feminist Liz Crow's comments echo our own opinions:

'I've always assumed that the most urgent Disability civil rights campaigns are the ones we're currently fighting for - employment, education, housing, transport etc., etc., and that next to them a subject such as sexuality is almost dispensable. For the first time now I'm beginning to believe that sexuality, the one area above all others to have been ignored, is at the absolute core of what we're working for (...) It's not that one area can ever be achieved alone - they're all interwoven, but you can't get closer to the essence of self or more "people-living-alongside-people ... than sexuality, can you?' (Crow, 1991: 13).

A final set of issues arose for me during the research. These related to my growing academic interest in narrative and biographical sociology. A particular example of this is Ken Plummer's book, *Telling Sexual Stories*, which is discussed in the book's conclusion. His work echoed my views and reinforced what we were trying to do with our research. He suggests: 'Rights and responsibilities are not "natural" or "inalienable" but have to be invented through human activities and built into the notions of communities, citizenship and identities. Rights and responsibilities depend upon a community of stories which make those same rights plausible and possible. They accrue to people whose identities flow out of the self-same communities. Thus it is only as lesbian and gay communities started to develop and women's movements gathered strength that stories around a new kind of citizenship became more and

more plausible. The nature of our communities - the languages they use, the stories they harbour, the identities they construct, the moral/political codes they champion - move to the centre stage of political thinking' (Plummer, 1995: 150).

Connecting with my previous work on identity, my interest in agency, and my philosophical allegiances with post-structuralist thought, Plummer's work was the benchmark for my writing.

## HOW DID WE GO ABOUT IT?

Working together, we decided to research a book which covered the range of issues in a coherent and fairly comprehensive way. This involved drawing up a loose schedule of areas to be explored in interviews with as many disabled people as possible. We looked at what little was already available, and we brainstormed from our own experience: we felt that our own lives and feelings were very relevant to the process. Rather than trying to achieve some spurious objectivity or distance, we acted as key informants and research participants.

Our sample was drawn from people of our own acquaintance, and from people who answered adverts or followed up requests published in a range of journals, including Disability Now and The Pink Paper. Eventually, it comprised 44 people: almost exactly equal numbers of men and women, but as many gay, lesbian and bisexual respondents as heterosexual. Clearly the British population does not comprise equivalent numbers of gay and straight individuals: the sample was skewed by our own contacts and biographies, and by the fact that gay people seemed more likely to come forward, and more willing to talk, than many straight people. We were not unduly alarmed at this situation: a greater concern was the small number of Black or Asian respondents, and the fact that the majority of participants were active in the disability movement. We made efforts to redress these imbalances, and were explicit about these limitations in the final publication: our lack of time and resources prevented us doing more to equalise the sample. We have never claimed to be representative, in a statistical sense: we are not saying 'this is the experience of all disabled people', we are saying 'this is what some disabled people have experienced, and these are our conclusions' .

As time went on, we used a greater variety of methods: we included letters which people wrote to us; some people made tapes of their own; we used progressively less structured formats. It was our intention to

document the lives and experiences of disabled people, and we felt a commitment to the individuals involved, rather than the social scientific community or a particular sense of methodological rigour. In this we felt supported by developments such as the work of Ken Plummer (1995) and Tim Booth (1996), both of whom have espoused narrative techniques and the gathering of personal stories within sociology. Perhaps the most obvious sign of this focus on life-story are the personal accounts between each chapter in the book: we decided to include these in order to convey the richness of the material we had gathered, and to give participants a chance to speak for themselves, and also, it has to be admitted, to achieve the target length which the publishers had set for us.

This last point indicates the pragmatism which underlay our methodology. As long as we were faithful to the participants, by which we meant basic ethical commitments not to misrepresent, betray confidentiality, or distort, we were content to follow their interests and allow the project to develop organically. The scope of the research was very broad: in an area which had not been investigated before, and with the paucity of records of disabled people's lives, we felt that we could afford to cast our net wide, and to sacrifice some rigour and some exactness. Many topics are not adequately explored: pregnancy and parenting, for example, or sexual abuse. Other people are generating more comprehensive accounts of these areas.

Certain problematic issues surfaced during the research process. For example, we had to deal with disclosure of sexual abuse from a number of participants, which was a topic we felt that we did not have the time or expertise to cope with effectively. We agreed that we would not ask questions, probe or analyse responses about sexual abuse, although we would include material in the book. This aspect of the work was one of the most distressing features of the research, and we would support the new initiatives which have developed to combat abuse.

A second issue concerns the willingness of participants to discuss matters, of personal relationships and sexual activity. The disability community as a whole does not readily discuss these private dimensions of life as a disabled person in our experience. We have argued that this area is as political as many of the issues which we do discuss and campaign about. Disabled people, in general, may lack the language or confidence to discuss matters of sex and love: this is a product of disempowerment, and a lack of effective sex education, and the minimal expectations of family, friends, carers and professionals. If interventions

are made - for instance, SPOD (Sexual Problems of the Disabled), they are often unhelpful because they are mechanistic, depoliticised, and outdated. In Britain, as a whole, discussion of sex is largely taboo: we are a nation of prudes, subject to immediate embarrassment over personal matters. Initiatives such as the Outsiders Club, on the other hand, aim to sexualise disability but run the risk of exploitation, voyeurism and abuse by failing to work within a disability equality perspective.

We found that many respondents were able to talk in general about their lives, and in abstract about issues of identity and imagery and barriers, for example, but found it difficult to talk specifically about relationships or sexuality. Some respondents would only respond to issues in political terms: they would talk about what they believed to be an appropriate and correct response to sexual matters, rather than about their own feelings and desires. However, enough respondents felt comfortable and willing to discuss the details of their sexual lives to enable us to include discussion of such personal experiences, although these were more likely to be women than men, and lesbian or gay people than straight people.

A third problem was represented by the small minority of respondents, all men, who reported behaviours with which we could not empathise: behaviours which were restrictive of other people's sexual and civil rights, and sometimes verged on abuse. Examples might include use of pornography or prostitution, or exploitative relations with other people. Given that our first commitment was to representing the views and experiences of disabled people faithfully, we felt anxious about censoring or judging the accounts provided by disabled people. However, we also felt that integrating disabled people in society, enabling access, and achieving civil rights should not be at the cost of oppressing other people in society, particularly women. We attempted to balance such testimonies, then, with other accounts by disabled people which were explicitly anti-sexist or opposed to abusive relationships, rather than excluding any material. Moreover, in the chapter on "Bad Sex" , we explored our own ethical standpoint on inappropriate sexual relations. This was not without its complications, however, as we ourselves held a range of views about what constituted a healthy or positive sexual relationship: none of us necessarily advocated monogamous pair-bonding as the only option, but we had different opinions as to the value of non-committed or casual encounters.

Other differences between authors inevitably occurred during the writing period, as our various biographies influenced our response to the

material, and our feelings about the style and direction of the text. One of us is predominantly a trainer, organiser and activist; another is a psychotherapist and counselling lecturer; a third is an academic. These differences meant that we approached the material in different ways, and had different aims for the final book. We would probably argue that this range of experience, wedded to a common concern for disability equality and sexual liberation, ensured that the book was balanced and broad in its appeal. However, at various times it led to differences over our authorial voice: how political could we be? How informal? How academic? Given that Cassell had commissioned a book with a predominantly academic readership, it was the sociological criteria that generally won through, although we would hope that the text is also both accessible and political.

## WHAT DID WE HOPE TO ACHIEVE?

This account of the research underlying *The Sexual Politics of Disability* may sound complacent, and lacking in academic professionalism. However, it was our intention to pave the way for others, and to produce a readable text which gave a voice to disabled people, not to provide the final word on this topic. It was our hope that a variety of people would read the book, and would think of disabled people differently as a consequence. We set out to demonstrate that disabled people can be just like other people; that physical restrictions are not the main issue in disabled sexuality; and that the sexual rights of disabled people need to be met, just as much as the civil and political rights.

We thought of our audience as a broad one: lay readers, academics, professionals, but most of all disabled people. We hoped that disabled people would recognise their own experiences, and would feel validated by the accounts we published. We placed the research within our broader understanding of empowerment, which for us is as much about personal and emotional developments as it is about political and structural change: in the book, and in our professional work, we balance a need for barrier-removal and civil rights, with a need to support individuals to develop a more positive self-image and a sense of pride and self-worth. To orient ourselves towards the early origins of the disability movement, we work within the tradition established by the Liberation Network of People with Disabilities, as much or more than that represented by the Union of Physically Impaired Against Segregation.

It is difficult to say whether these ambitions have been fulfilled; voices and reactions filter back to us which are largely positive, from women and men who understand and respect what we have tried to do. Reviews have thus far been positive, sometimes deliriously so. It is particularly heartening that people included in the book have found it accurate and helpful. There has certainly been considerable interest in the book, as well as some scepticism from the more ideologically rigorous members of the disability movement who pick up on semantic details (describing the social model as "an analysis of the experiences of disabled people" did not go down well). But the true mark of the book's success in achieving its ambitions will be a more long-term appraisal and response from disabled people in general, and in the extent to which it challenges the prevailing view of disabled people as asexual, which is an intangible consequence which we will never be able to measure.

Of course, the research and writing has been a learning experience. There are many ways in which I would do things differently in future. Most of these are minor points: the major ones are about being systematic, not being too ambitious, allowing enough time. I'm not sure I would do this type of research and writing collaboratively again: we succeeded, but I feel a need to exercise more control over projects than I was able to on this occasion. I'm now more likely to work with just one other person. I stick with my view that it is important to gather primary data and to give disabled people a voice, and that analysis and theory is secondary to that. However, in my current work on disabled childhood, because it is a more sociological project, there will be more analysis and discussion.

## CONCLUSION

The million dollar question remains: is *The Sexual Politics of Disability* emancipatory research? To be honest, I don't know and I don't really care. I am a pluralist, and would rather follow my own intellectual and ethical standards, rather than trying to conform to an orthodoxy. I don't follow recipes when I cook, and I'm not keen on following imposed rules when I research. However, I think I share the basic commitment which underlies the notion of emancipatory research, although it is for others to judge by the results.

My editor has asked me to answer three questions:

- 1. Is the research initiated by disabled people rather than by academics?*

Well, yes and no. Two of the authors were not academics and one was. We are all disabled people. We had political objectives, namely disability equality and civil rights. However, no representative self-organised group of disabled people initiated the project.

*2. Does the research adhere to the social model of disability?*

Everything I do adheres to the social model of disability, according to my own interpretation of it. I'm not prepared to ignore issues such as impairment, but in general I think I can answer yes. The book opens with a chapter on social barriers, after all.

*3. Does it involve unprecedented levels of participation, accountability and reciprocity?*

Not really. We were broadly accountable to our research participants. We let them shape the research interviews, in many cases to write their own accounts, and their own priorities influenced the format and scope of the final text. We talked to other disabled people, organisations and academics. I was not, and am not, prepared to let other people control what I write, or dictate the appropriate political stance. In this project there was not enough time or resources to enable people to check over the text or comment on it. While I would always welcome advice and feedback, I'm not sure I'd ever want to be accountable to anyone other than my publisher and my conscience.

I have a certain scepticism about the notions of emancipatory research developed by Mike Oliver (1992) and Gerry Zarb (1992), among others. Different forms of social research may be more or less applied or pure, and more or less allied to the needs of particular groups within the disability movement. While disability studies emerged from the disability movement, it is not contiguous to it: there are obviously major areas of overlap, and a general ideological commitment to the ideals of the disability movement on the part of disability studies academics, but it would be wrong to see disability studies as only providing policy interventions or social analysis for political goals. We need to have a range of models for the connection between theory and practice.

*The Politics of Disablement*, for instance, is a sociological work, without direct recommendations or policy points (Oliver, 1990). However, it has had a major impact on the lives of disabled people, because it gave intellectual credibility to the social model, and validated the analysis and

direction of the disability movement. It may be fairly inaccessible, but thousands of disabled people have read it, and their consciousness has been altered as a result. This has enabled them to become activists in the movement, to argue more forcefully for disability rights, and to campaign for a better deal for disabled people. Other works, for instance Colin Barnes' *Disabled People in Britain and Discrimination* (1991), offered social policy evidence for the extent of disabling barriers in society: it was a critical tool in demonstrating the reality of social exclusion and the need for anti-discrimination legislation, as Rachel Hurst has argued (Hurst, 1995). Therefore research differs in the way it affects policy and practice - some operates directly, some indirectly.

It is my belief that the criteria which Mike Oliver presents for emancipatory research are too strict, and that he is naive or disingenuous in believing that his work has benefited nobody other than himself. He may have profited financially, by a few thousand pounds, and he may have developed a reputation as a widely published and cited academic. However, as an academic, he could have made a living out of lecturing and researching on any number of topics: he did not have to choose disability. He has used his status and his position to support and develop the disability movement, and his books have contributed both directly and indirectly to disabled people's increased political consciousness, and to their success in grasping specific goals.

There is a certain tendency within the disability movement, which I have nicknamed "Maoism" (although the term is not used in a strict ideological sense), which is suspicious of academic work, and venerates the activist and the grassroots at the cost of the researcher and the writer. From this perspective, academics are parasites on the movement, who would be better off on the streets or staffing their local organisations of disabled people. The movement is the key, and the academics are an optional extra. All research with disabled people is suspect, and organisations should not co-operate with those who are 'seeking to make a career out of exploiting disabled people'. It may be guessed that I do not find this a helpful or constructive approach.

I do not believe that academics should be spokespeople for the disability movement: the voice of disabled people are the representative organisations of the disability movement, not individuals regardless of expertise or experience. However, academics have a valuable part to play in the development of our understanding of the world as experienced by disabled people. It is a very privileged position: it depends on being able

to stand back, and to observe, and to think and reflect. It depends on time, and space, and money. And it would be a pretty poor disability studies researcher who did not repay that privilege by devoting time and energy (and money) to supporting and building the organisations of the disability movement.

The precedent which I offer for the relationship between researchers and the movement is the way in which other scholars - feminists and lesbian and gay writers are those with whom I am most familiar - have worked within identity politics. While there have been tensions, I do not observe in these parallel contexts the same demands being made of intellectuals, or the suspicion and resentment that sometimes seems evident in the disability movement. Perhaps that is because disabled people have a tradition of being exploited by researchers; or perhaps that it is because the relative poverty of most disabled people, and the relative wealth of most academics, is more stark a difference than the comparable gap between feminist women and feminist researchers or lesbian/gay people and writers. However, I do hope that disability studies does not repeat that precedent too closely: rather than following feminism and lesbian/gay studies into the academy and into increasingly complex and arid discussions of theory, I would hope that disability studies research retains its accessibility for ordinary readers, and its commitment to documenting the lives and priorities of disabled people. This form of openness is my main priority. I want my work to make a difference, but I have no illusions about its impact. Books don't change the world. People do.

## REFERENCES

BARNES, C. (1991) *Disabled People in Britain and Discrimination*. London: Hurst and Co.

BOOTH, T. (1996) 'Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties', in L. Barton, ed., *Disability and Society*. London: Longman.

CROW, L. (1991) 'Rippling Raspberries: Disabled Women and Sexuality', unpublished MSc dissertation, South Bank Polytechnic.

DIAMOND, M. (1984) 'Sexuality and the Handicapped', in R.P. Marinelli and A. Dell Orto, eds, *The Psychological and Social Impact of Physical Disability*. New York: Springer Publishing.

FINGER, A. (1992) *Forbidden Fruit*, *New Internationalist*, 233: 8-10.

HUNT, P. (1966) *Stigma*. London: Geoffrey Chapman.

- HURST, R. (1995) 'International Perspectives and Solutions', in G. Zarb, ed., *Removing Disabling Barriers*. London: Policy Studies Institute.
- MORRIS, J. (1989) *Able Lives*. London: Women's Press.
- MORRIS, J. (1991) *Pride Against Prejudice*. London: Women's Press.
- OLIVER, M. (1983) *Social Work with Disabled People*, Basingstoke: Macmillan.
- OLIVER, M. (1990) *The Politics of Disablement*, Basingstoke: Macmillan.
- OLIVER, M. (1992b) Changing the social relations of research production, *Disability, Handicap & Society*, 7 (2): 101-114.
- PLUMMER, K. (1995) *Telling Sexual Stories*. London: Routledge.
- SHAKESPEARE, T. GILLESPIE-SELLS, K. and DAVIES, D. (1996) *The Sexual Politics of Disability: Untold Desires*. London: Cassell.
- ZARB, G. (1992) 'On the road to Damascus; first steps towards changing the relations of disability research production', *Disability, Handicap & Society*, 7 (2): 125-38.