

Appendices & Bibliography (in *The Sexual Politics of Disability: Untold Desires*, Tom Shakespeare, Kath Gillespie-Sells & Dominic Davies (1996) Cassell, pp 210-216)

## **Appendix One**

### **Contributors to the research**

The following are pen-pictures of the people who contributed to the research. Some names have been changed by request, other names have been changed by default. The identifying features are mostly the ones specified by participants, rather than author descriptions. Where sexuality is not mentioned, the participant is presumed heterosexual.

**Andy:** working-class man with learning difficulties, early thirties, unemployed.

**Ben:** professional gay man, uses a wheelchair.

**Beth:** forty-eight years old, married to second husband, two children, two stepchildren and two grandchildren, worked as an education professional, diagnosed with multiple sclerosis in 1983.

**Bill:** forty-eight year old Scottish, middle-class gay man. Has epilepsy, and has retired for health reasons.

**Binnie:** twenty-six year old heterosexual working-class deaf woman, with deaf parents.

**Charles:** twenty-six year old heterosexual, blind, wheelchair-user.

**Daniel:** thirty-two year old middle-class gay man with congenital mobility impairment.

**David:** thirty-nine year old, gay, has haemophilia and scoliosis and is HIV-positive.

**Eddie:** twenty-nine year old working-class heterosexual artist, with spina bifida.

**Elizabeth:** fifty-eight year old bisexual artist, has multiple sclerosis.

**Frances:** fifty-five year old lesbian trainer/consultant/therapist.

**Gloria:** forty-three year old system survivor, has cerebral palsy, was married with children, came out as a lesbian aged thirty-nine.

**Jazz:** Jordanian-origin woman in her thirties, worked in disability organizations, now in film, has brittle bones and uses a wheelchair.

**Jenny:** lesbian in her forties, works in a disability organization in London.

**Jeremy:** thirty-eight year old, gay, works for a local authority in London. His impairment is a muscle weakness called amyoplasia congenital.

**Jo:** twenty year old black bisexual woman with physical impairment.

**Julie:** thirty-five year old lesbian, working-class, Irish background, musician/performer, and survivor of the mental health system.

**Kirsten:** blind lesbian, works in a disability organization.

**Kit:** middle-class lesbian, working in disability movement, congenital mobility impairment.

**Louise:** forty-one year old middle-class lesbian.

**Mark:** thirty-two year old gay man, volunteer childcare worker, double incontinence.

**Michael:** twenty-three year old gay man.

**Neil:** Scottish man, father, diabetic with visual impairment, works in the disability field.

**Nigel:** gay man with a learning difficulty, and a physical impairment.

**Ronan:** forty-eight year old, gay man, previously worked for a local authority, has a colostomy and cancer and is HIV positive.

**Patrick:** twenty-nine year old Irish gay man, middle-class, systems analyst, is partially sighted.

**Paul:** working-class man with learning difficulties, early thirties, unemployed.

**Paula:** woman in her thirties, developed multiple sclerosis at age twenty-two.

**Pauline:** twenty-nine year old working-class lesbian Yorkshire woman, works in disability field.

**Penny:** thirty-five year old writer, with arthritis.

**Phillipe:** thirty-nine year old deaf gay man, middle-class, with hearing parents.

**Ruth:** forty-three year old Jewish lesbian, middle-class mother.

**Sara:** thirty-six year old, Irish-origin lesbian, works as a counsellor, has children. Has paraplegia.

**Stuart:** heterosexual man with muscular dystrophy, training to be lawyer, father.

**Sue:** works in disability field, mother, has chronic asthma.

**Veronica:** middle-class, bisexual, woman in forties, working in voluntary sector in London, congenital visual impairment.

**Zebedee:** fifty-seven year old, working-class heterosexual man, blind and uses a wheelchair.

**Zorah:** thirty-four year old, Jewish, middle-class lesbian, arts worker in London. Has had an impairment since age twenty-seven, also has mental health problems.

There were also two anonymous and unidentified questionnaires, and there are several additional quotations in the book from women interviewed in the Sexual Health and Equality (SHE) Project, and from other people we talked to. Not including these, but including the additional accounts between chapters, the research involved eight heterosexual women, ten lesbians and three bisexual women, and nine heterosexual men and twelve gay men. Most of our respondents were English, Irish or Scottish: two identified as Jewish, one as Jordanian, and three as black or Asian.

## Appendix Two

### Resources

Where there is a charge for leaflets and other publications, this is indicated by an asterisk.

Accessible nightclubs: The Black Orchid (Nottingham); The Hacienda (Manchester); Leadmill (Sheffield); Ministry of Sound (Elephant & Castle, London); The Mirage (Luton); The Riverside (Newcastle); Zap Club (Brighton).

Arthritis Care (publishes *Our Relationships, Our Sexuality* leaflet\* for young people), 18 Stephenson Way, London NW1 2HD, tel. 0171 916 1500

*Disability Now* (monthly newspaper\*), SCOPE, 12 Park Crescent, London W1N 4EQ

*Disability, Pregnancy and Parenthood International* (quarterly journal\*), Arrowhead Publications, 1 Chiswick Staithe, London W4 3TP

DISCERN (agency working around sexuality and disability), Suite 6, Clarendon Chambers, Clarendon Street, Nottingham NG1 5LN, tel. 0115 474147

Handidate Friendship Agency: The Wellington Centre, Chevallier Street, Ipswich, Suffolk, tel. 01473 226950

'It's Okay!' ('international consumer quarterly on sexuality, sex and disability'\*), Phoenix Counsel Inc., One Springbank Drive, St Catherine's, Ontario, Canada L2S 2KL

London Lesbian and Gay Switchboard: tel. 0171 837 7324 (local support lines available)

Maternity Alliance Disability Working Group (information pack available\*), 15 Britannia Street, London WC1X 9JN, tel. 0171 837 1265

National AIDS Helpline: tel. 0800 567 123

Outsiders Club, PO Box 4ZB, London W1A 4ZB, tel. 0171 739 3195

Parentability (resource list available\*), National Childbirth Trust, Alexandra House, Oldham Terrace, Acton, London W3 6NH, tel. 0181 992 8637

REGARD (national network of disabled lesbians, gays and bisexuals), BM REGARD, London WC1N 3XX

SAR (Dutch surrogacy organization), Postbus 875, 3700 AA Zeist, The Netherlands, tel. (00 131 3404) 60390

Spinal Injuries Association (publish booklets on sex, specific for men/women, straight/gay\*, including information on erection assistance procedures), Newpoint House, 76 St James' Lane, London N10 3DF, tel. 0181 444 2121

SPOD (Association to Aid the Sexual and Personal Relationships of People with a Disability, counselling line, leaflets\*), 286 Camden Road, London N7 0BJ, tel. 0171 607 8851

## Bibliography

- Anon. (1990) 'Sexual harassment in the disabled community', *Disability Arts in London*, June, pp. 14-15.
- Appleby, Yvon (1990) 'Access Limited: an exploration into why disabled lesbians are so invisible within the lesbian community', Staffordshire Polytechnic unpublished dissertation.
- Appleby, Yvon (1993) 'Disability and "compulsory heterosexuality"' in Celia Kitzinger and Sue Wilkinson, *Heterosexuality*. London: Sage.
- Appleby, Yvon (1994) 'Out in the margins', *Disability and Society*, vol. 9, no. 1, pp. 19-32.
- Aspen (1994), 'Don't expect me to put up with your shit', *bad attitude*, no. 6, p.23.
- Atkinson, D. and Williams, F. (1990) *Know Me As I Am - An Anthology of Poetry, Prose and Art by People with Learning Difficulties*. London: Hodder and Stoughton in association with the Open University Press.
- Bailey, Ruth (1996) 'Prenatal testing and the prevention of impairment: a woman's right to choose?' in J. Morris (ed.) *Encounters with Strangers*. London: Women's Press, pp. 143-67.
- Banim, Maura and Guy, Alison (1995) 'Peer sex education with disabled people', unpublished paper, Social Aspect of AIDS Conference, London.
- Barnes, C. (1991) *Disabled People in Britain and Discrimination*. London: Hurst and Co.
- Barnes, C. (1992) *Disabling Imagery*. Derby: BCDODP.
- Barton, Len (1987) *The Politics of Special Educational Needs*. Lewes: Falmer Press.
- Begum, Nasa (1992) 'Disabled women and the feminist agenda', *Feminist Review*, no. 40, Spring, pp. 70-84.
- Begum, N., Hill, M. and Stevens, A. (1994) *Reflections: Views of Black Disabled People on Their Lives and Community Care*. London: CCETSW;

- Blackwell-Stratten, M., Bestin, M. L., Mayerson, A. B. and Bailey, S. (1988) 'Smashing icons' in M. Fine and A. Asch (eds) *Women with Disabilities: Essays in Psychology, Culture and Politics* Philadelphia: Temple University Press, pp. 306-32.
- Bogle, Jane Elder and Shaul, Susan L. (1981) 'Body image and the woman with a disability' in David Bullard and Susan Knight (eds) *Sexuality and Physical Disability: Personal Perspectives*. St Louis: C. V. Mosby & 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: Longmans.
- Booth, Tim and Booth, Wendy (1994) *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. Buckingham: Open University Press.
- Brown, Hilary (1994) "'An ordinary sexual life?": a review of the normalisation principle as it applies to the sexual options of people with learning disabilities', *Disability and Society*, vol. 9, no. 2, pp. 123-44.
- Browne, S., Connors, D. and Stern, N. (1981) *With the Power of Each Breath: A Disabled Woman's Anthology*. San Francisco: Cleis Press.
- Bullard, D. and Knight, S. (eds) (1981) *Sexuality and Physical Disability*. St Louis: C. V. Mosby & Co.
- Campbell, Jane and Oliver, Michael (1996) *Disability Politics*. London: Routledge.
- Campbell, John (1995) 'Disabled People International', *UK Coalition of People Living with HIV and AIDS Newsletter*, no. 7.
- Campion, Mukti Jane (1990) *The Baby Challenge*. London: Tavistock/ Routledge.
- Campling, Jo (1979) *Better Lives for Disabled Women*. London: Virago.
- Campling, Jo (ed.) (1981) *Images of Ourselves*. London: Routledge and Kegan Paul.

- Chapkis, Wendy (1986) *Beauty Secrets: Women and the Politics of Appearance*. London: Women's Press.
- Coleridge, P. (1993) *Disability, Liberation and Development*. Oxford: Oxfam.
- Comfort, Alex (1978) *Sexual Consequences of Disability*. Philadelphia: Stickley.
- Connell, R. W. (1995) *Masculinities*. Cambridge: Polity.
- Cooney, Kate (1991) 'The girl can't help it', *The Guardian*, 2 January.
- Corbett, Jenny (1994) 'A proud label: exploring the relationship between disability politics and gay pride', *Disability and Society*, vol. 9, no. 3.
- Craft, Michael and Craft, Ann (1978) *Sex and the Mentally Handicapped*. London: Routledge and Kegan Paul.
- Cross, M. (1994) 'Abuse' in L. Keith (ed.) *Mustn't Grumble*. London: Women's Press.
- Crow, Liz (1991) 'Rippling raspberries: disabled women and sexuality', unpublished MSc dissertation, South Bank Polytechnic.
- Cumberbatch, G. and Negrine, R. (1992) *Images of Disability on Television*. London: Routledge.
- Davis, Ken (1993) 'On the movement' in J. Swain et al., *Disabling Barriers, Enabling Environments*. London: Sage.
- Deegan, Mary Jo and Brooks, Nancy A. (eds) (1985) *Women and Disability: The Double Handicap*. New Brunswick, NJ: Transaction Books.
- Degener, T. (1992) 'The right to be different: implications for child protection', *Child Abuse Review*, vol. 1, pp. 151-5.
- Diamond, Milton (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.
- Driedger, Diane (1989) *The Last Civil Rights Movement: Disabled Peoples' International*. London: Hurst & Co.
- Fine, Michelle and Asch, Adrienne (1985) 'Disabled women: sexism without the pedestal' in Mary Jo Deegan and Nancy

- A. Brooks (eds) *Women and Disability: The Double Handicap*. New York: Transaction Books, pp. 6-22.
- Fine, Michelle and Asch, Adrienne (1988) *Women with Disabilities: Essays in Psychology, Culture and Politics*. Philadelphia: Temple University Press.
- Finger, Anne (1991) *Past Due: A Story of Disability, Pregnancy and Birth*. London: Women's Press.
- Finger, Anne (1992) 'Forbidden fruit', *New Internationalist*, no. 233, pp. 8-10.
- Finkelstein, Vic(1980) *Attitudes and Disabled People*. New York: World Rehabilitation Fund.
- Finkelstein, V. (1993) 'Towards a psychology of impairment' in J. Swain et al., *Disabling Barriers, Enabling Environments*. London: Sage.
- Foucault, M. (1988) 'Power and sex' in L. D. Kritzmann (ed.) *Politics, Philosophy, Culture*. London: Routledge.
- French, Sally (1996) 'Out of sight, out of mind: the experience and effects of a "special" residential school' in J. Morris (ed.) *Encounters with Strangers*. London: Women's Press, pp. 17-47.
- Fulcher, Gillian (1989) *Disabling Policies?* Lewes: Falmer.
- Gerschick, Thomas J. and Miller, Adam Stephen (1995) 'Coming to terms' in D. Sabo and D. Gordon (eds) *Men's Health and Illness*. London: Sage, pp. 183-204.
- Gillespie-Sells, K. and Ruebain, D. (no date) *Double the Trouble, Twice the Fun*. London: Channel 4.
- Goffman, E. (1968) *Stigma*. Harmondsworth: Pelican.
- Gooding, Caroline (1994) *Disabling Laws, Enabling Acts*. London: Pluto.
- Greengross, Wendy (1976) *Entitled to Love: The Sexual and Emotional Needs of the Handicapped*. London: Malaby Press.
- Gregory, Susan and Hartley, Gillian (eds) (1991) *Constructing Deafness*. London: Pinter Publishers with Open University Press.

- Greig, G. (1995) 'HIV/AIDS and people with visual impairment', unpublished dissertation, University of Sunderland.
- Griffiths, Ernest, compiler (1975) 'Sexual dysfunctions associated with physical disabilities', *Archives of Physical Medicine and Rehabilitation*, no. 56, pp. 8-13.
- Hanna, William and Rogovsky, Betsy (1991) 'Women with disabilities: two handicaps plus', *Disability, Handicap and Society*, vol. 6, no. 1, pp. 49-63.
- Hardiker, P. (1994) 'Thinking and practising otherwise: disability and child abuse', *Disability and Society*, vol. 9, no. 2, pp. 257-63.
- Hasler, Frances (1993) 'Developments in the disabled people's movement' in J. Swain et al., *Disabling Barriers, Enabling Environments*. London: Sage.
- Hearn, Kirsten (1988a) 'A woman's right to cruise' in Christine McEwen and Sue O'Sullivan (eds) *Out the Other Side: Contemporary Lesbian Writing*. London: Virago.
- Hearn, Kirsten (1988b) 'Oil What about us' in Bob Cant and Sue Hemmings (eds) *Radical Records: 30 Years of Lesbian and Gay History*. London: Routledge.
- Hearn, Kirsten (1991) 'Disabled lesbians and gays are here to stay' in Tara Kaufmann and Paul Lincoln, *High Risk Lives*. Bridport: Prism Press.
- Hill, Mildrette (1994) 'They are not our brothers' in Nasa Begum, Mildrette Hill and Andy Stevens (eds) *Reflections: Views of Black Disabled People on Their Lives and Community Care*. London: CCETSW, pp. 68-80.
- Humphries, S. and Gordon, P. (1992) *Out of Sight: The Experience of Disability 1900-1950*. Plymouth: Northcote House.
- Keith, L. (1992) 'Who cares wins?'. *Disability, Handicap and Society*, vol. 7, no. 2, pp. 167-75.
- Keith, L. (1994) *Mustn't Grumble*. London: Women's Press.

- Keith, L. (1996) 'Encounters with strangers' in J. Morris (ed.) *Encounters with Strangers*. London: Women's Press, pp. 69-88.
- Keith, L. and Morris, J. (1996) 'Easy targets: a disability rights perspective on the "children as carers" debate' in J. Morris (ed.) *Encounters with Strangers*. London: Women's Press, pp. 89-115.
- Kelly, L. (1992) 'The connections between disability and child abuse: a review of the research evidence', *Child Abuse Review*, vol. 1, pp. 157-67.
- Kevles, D. J. (1986) *In the Name of Eugenics*. Harmondsworth: Penguin.
- Lamb, Brian and Layzell, Susan (1994) *Disabled in Britain: A World Apart*. London: SCOPE.
- Lancaster-Gaye, D. (ed.) (1972) *Personal Relationships, the Handicapped and the Community*. London: Routledge and Kegan Paul.
- The Lancet* (16 July 1949) 'Disabilities. 34. Homosexuality', pp. 128-9.
- Lemert, E. M. (1951) *Social Pathology*. New York: McGraw-Hill.
- Lonsdale, Susan (1990) *Women and Disability: The Experience of Physical Disability among Women*. Basingstoke: Macmillan.
- Mairs, Nancy (1992) 'On being a cripple' in Linda McDowell and Rosemary Pringle (eds) *Defining Women*. Cambridge: Polity Press, pp. 56-66.
- Martin, J., Meltzer, H. and Elliot, D. (1988) *The Prevalence of Disability among Adults*. London: HMSO.
- Morris, Jenny (1989) *Able Lives*. London: Women's Press.
- Morris, Jenny (1991) *Pride Against Prejudice*. London: Women's Press.
- Morris, Jenny (1993a) *Independent Lives: Community Care and Disabled People*. Basingstoke: Macmillan.
- Morris, Jenny (1993b) 'Gender and disability' in J. Swain et al., *Disabling Barriers, Enabling Environments*. London: Sage.

- Morris, Jenny (1996) *Encounters with Strangers: Feminism and Disability*. London: Women's Press.
- Murphy, R. (1987) *The Body Silent*. London: Phoenix House.
- Oakley, Ann (1972) *Sex, Gender and Society*. London: Maurice Temple Smith.
- Oliver, Michael (1990) *The Politics of Disablement*. London: Macmillan.
- Olsen, R. (1996) 'Young carers: challenging the facts and politics of research into children and caring', *Disability and Society*, vol. 11, no.1, pp.41-54.
- Owens, Tuppy (1986) *Practical Suggestions*. London: The Outsiders Club.
- Pagel, Martin (1988) *On Our Own Behalf: An Introduction to the Self-organisation of Disabled People*. Manchester: GMCDP Publications.
- Parker, Gillian (1993) *With This Body: Caring and Disability in Marriage*. Buckingham: Open University Press.
- Parsons, Talcott (1951) *The Social System*. New York: Free Press.
- Pearson, Veronica and Klook, Andrew (1989) 'Sexual behaviour following paraplegia: an exploratory study in Hong Kong', *Disability, Handicap and Society*, vol. 4, no. 3, pp. 285-95.
- Plummer, Ken (1995) *Telling Sexual Stories*. London: Routledge.
- Rae, Anne (1984) 'Refusing to be outsiders', *Spare Rib*, no. 145, pp. 18-20.
- Robinault, Isabel (1978) *Sex, Society and the Disabled*. Hagerstown, MD: Harper & Row.
- Saxton, Marsha and Howe, Florence (eds) (1988) *With Wings: An Anthology of Literature by and about Women with Disabilities*. London: Virago.
- Schwier, K. Melberg (1994) *Couples with Intellectual Disability Talk About Living and Loving*. Rockville, MD: Woodbine House.
- Seymour, Julie (1994) "'It's different from being loving": disablement, caring and marriage', BSA Conference paper.

- Shakespeare, Tom (1993) 'Disabled people's self-organisation: a new social movement?', *Disability, Handicap and Society*, vol. 8, no. 3, pp. 249-64.
- Shakespeare, Tom (1994a) 'Cultural representation of disabled people: dustbins for disavowal?', *Disability and Society*, vol. 9, no. 3, pp. 283-99.
- Shakespeare, Tom (1994b) 'Disabled by prejudice', *The Pink Paper*, 1 April, p.13.
- Shakespeare, Tom (1995) 'Back to the future? New genetics and disabled people', *Critical Social Policy*, vol. 44/45, pp. 22-35.
- Sobsey, D. and Doe, T. (1991) 'Patterns of sexual abuse and assault', *Sexuality and Disability*, vol. 9, no. 3, pp. 243-59.
- Spinal Injuries Association (no date) *Sexuality and Spinal Cord Injury*. London: SIA.
- Sutherland, Allan (1981) *Disabled We Stand*. London: Souvenir Press.
- Swain, John et al. (1993) *Disabling Barriers, Enabling Environments*. London: Sage.
- Thompson, David (1994) 'Men with learning disabilities' sex with men in public toilets: taking responsibility', BSA Conference paper.
- Thompson, K. and Andrzejewski, J. (1988) *Why Can't Sharon Kowalski Come Home*. San Francisco: Spinsters.
- Tiefer, Leonore (1995) *Sex Is Not a Natural Act*. Oxford: Westview Press.
- Udall, Elizabeth (1994) 'What? A nice girl like you?', *Independent*, 13 January.
- Vasey, Sian (1995) 'The experience of care', in Gerald Hales (ed.) *Beyond Disability*. London: Sage, pp. 82-7.
- Vernon, Ayesha (1996) 'A stranger in many camps: the experiences of disabled black and ethnic minority women' in J. Morris (ed.) *Encounters with Strangers*. London: Women's Press, pp. 48-69.
- Vernon, Glynn (1995) 'Truly, madly, deeply' in *Disability Now*, February, p.22.

- Westcott, Helen (1993) *Abuse of Children and Adults with Disabilities*. London: NSPCC.
- Westcott, Helen and Cross, Merry (1996) *This Far and No Further; Towards Ending the Abuse of Disabled Children*. Birmingham: Venture Press.
- Williams, Christopher (1993) 'Vulnerable victims? A current awareness of the victimisation of people with learning disabilities', *Disability, Handicap and Society*, vol. 8, no. 2, pp. 161-72.
- Wolfensburger, w: (1972) *The Principle of Normalization in Human Services*. Toronto: NIMR.
- WHO (1980) *International Classification of Impairments, Disabilities and Handicaps*. Geneva: WHO.