CHAPTER 11

The Dynamics of Partnerships and
Professionals in the Lives of People with
Learning Difficulties

Deborah Phillips

(From Barnes, C and Mercer G. (eds.) 2004: ***Disability Policy and
Practice: Applying the Social Model*** , Leeds: The Disability Press,
160-174).

Introduction

Building on my own recent research and utilising the narrative accounts
of women participants, this chapter sets out to explore some of the
inherent power dynamics evident in cared-for and the carer relationship.
Many of the women involved in this investigation related negatively to
the impact of professional judgements in the planning of their daily
routines and health needs. However, there was also evidence of strong
alliances between women and the female support staff who worked with
them. This chapter argues that the role of professionals, and the
emphasis on multi-agency partnerships and 'participation' in relation to
health and welfare practices, continues to ignore real partnerships with
people labelled as having 'learning difficulties'. Meanwhile, at the grass
roots level, changes are being witnessed in the introduction of non-
medicalised, alternative health practices as well as through a social
model understanding of learning difficulties.

'People don't usually listen to me; they just tell me what to do'
This statement was made by Beccy (a pseudonym as with all the names
of research participants), the first person I interviewed as part of my
research project. It highlights the controlling role of professionals in the
everyday lives of people labelled as having 'learning difficulties'. When I
met Beccy in her home, the table and floor were covered with piles of
papers, letters, files and so on that she had gathered together to show
me. Her life, she said, 'was laid out in these papers…all the details you
need to know.' She was nervous and repeatedly asked if I was a social
worker. Beccy seemed surprised that someone may be interested in
what she had to say, her side of the story, as opposed to 'telling her

what to do', and organizing her life.

Beccy's history, told in her own way, is probably somewhat different from the mound of literature she had spread out before her. She is a woman in her mid-thirties who lives independently in a small coastal village but also cares for her father who is nearby. She is physically disabled as well as being labelled as having learning difficulties. Beccy claims she has learning difficulties because she cannot cope with life like other 'normal people'. She is mother of two children, both of whom, she says 'were taken from me at birth by Social Services'. During the two year communication I had with Beccy, her life experiences consisted of a series of upheavals and transitions; parental problems, violent relationships, a planned then cancelled marriage, struggles with the benefit system and finances, plus the constant anxiety of her adopted children.

Beccy identified herself in a number of roles: as a mother, a daughter and a grown woman about to be married. However, these roles remain ambiguous. As a mother she is without children, as a daughter she is treated like an eternal child yet also positioned as carer of her father. As a woman, her sexuality is misplaced; from the 'crippled prostitute' to the victim of violent relationships and failed partnerships. Nonetheless, Beccy is also politically active and a strong campaigner for disabled people's rights. Her aim, she insists, is to get decent wheelchair access into all the pubs and places she likes and needs to go. Far from being a woman with learning difficulties it became clear that Beccy, like many other women interviewed, were in fact struggling with, negotiating and managing some very complicated life situations. Similar to Walmsley's (1994: 273) research, I also found participants who:

> presented images of themselves which were complex and multi faceted, a rounded picture of human beings struggling to make sense of their situations and relationships.

The 'learning difficulty' label, professionals and provision
However, this certainly is not the image generally associated with women labelled as having learning difficulties. In a historical context, prejudice and discrimination against such people has been deeply ingrained in society. Attitudes based upon psychological fear, superstition and notions of 'abnormal' or 'feebleminded' have evoked practices which promoted the 'systematic removal of disabled people from the mainstream of economic and social life' (Barnes 1991: 27). Silencing and segregating people in isolated institutions also led to them

being labelled and studied as a 'separate category of human beings' (Atkinson 1997: 14), with their histories recorded by others and identities constructed within medical and educational discourses (Gilman et al. 1997). Institutionalisation also brought about methods of classification in relation to a notion of 'normality'. This social construction, based on a concept of personal 'competence', relates to intellectual ability, but also extends to include normative and rational ways of behaving (Jenkins 1998; Dowse 2000; Goodley 2000). People are not only judged by their cognitive impairment, the label also incorporates assessments of 'challenging' or 'difficult behaviour.' Goodley claims these judgements are reflected in peoples' personal activities, stating that 'when they are allowed into the community; perfection is demanded' (2000: 43). Davis (1998: 103) sums this up by asserting that people with learning difficulties actually challenge Western conceptions of autonomy and individualism, and because of their 'difference' they are considered a threat to the basic social order. To put it simply, people labelled in this way have been, and continue to be, defined by what they cannot do, rather than what they can.

Medical intervention, the labelling process, 'special needs' educational assessments and the use of specialised terminology used in these programmes, play a predominant role in carving out notions of learning difficulty (Dumbleton 1998; Simpson 1999). A person is labelled in the terms of their pathology - what is wrong with them - as well as being allotted a particular grade or category. Impairment then becomes localised as the individual's problem, which in turn fulfils the classic 'personal tragedy' syndrome highlighted by Oliver (1996: 120). While it is not denied that some people who experience these conditions may require aid and support, this medical framework suggests the cause of learning difficulty is clear cut and definable. Ryan and Thomas, for example, argue that,

> … in very many instances the type of mental handicap is simply unknown … in even fewer cases is it possible to identify a precise cause, or describe the causal mechanisms involved in such a way that curative measures can be devised (1980: 16).

There is no overarching reason why these impairments are medically conceptualized or considered within the remit of professional control. Indeed, these boundaries falter when some impairments, like cerebral palsy or epilepsy, occur in people who are not labelled as having a learning difficulty, while other people labelled in this respect do not experience a specific impairment. In fact, the medical and nursing needs

of people with learning difficulties are really no different from the rest of the population (Hattersley 1987). Nonetheless, the powerful networks of biomedical control also extend to the production of 'new' medical knowledge (this can be witnessed in the increase in genetic technology), thus remaining a dominant influence in the lives - and potential lives - of people with learning difficulties.

This dilemma is evident in service provision. Although community care initiatives have placed emphasis upon developing needs-led and user-led services - an approach where the social model of disability is seen to override the medical - care assessment and planning procedures still remain predominately in the professional domain (Aspis 1997, 1999; Ramcharan 1997). This situation can be linked to New Labour's social policy programme where 'social justice' is now redefined in such terms as 'participation' and 'community' (Blair 1997,1999). The 'third way' for social care is based on moves away from those who provide the 'care', to the receivers of care: the individual, their carers and their families (Department of Health 1998: section 17). Such strategies have been criticised by public sector social workers, where the introduction of multidisciplinary agencies and partnerships (with voluntary and community sector) has marginalized and reduced social work to crisis management (Jordan 2001).

However, this marginalized position also applies to people labelled as having learning difficulties, where policies, and the emphasis on 'partnerships and inclusion', has also failed, thus remaining rhetorical as opposed to realistic. An example of this can be seen in the White Paper *Valuing People: A New Strategy for Learning Disability in the 21st Century* (Department of Health 2001). Not only have the proposed aims been under financed (Leason 2003), but according to Race (2003a) there is ample evidence that the medical model is alive and well, despite the White Paper recommendations. This conclusion transpired from a review of the position of learning difficulties in both academia and in professional training programmes for health and social workers (Race 2003b). Furthermore, criticism from user-led organisations involved in service planning remains problematic. Despite some exceptions, the practice seems to pivot on user involvement being regarded as a 'requirement' imposed by government, and thus another burden to contend with. The reality of creating real partnerships and hearing the voice of people with learning difficulties therefore remains locked in the traditional confrontational approach between service user and provider (Beresford 2003a).

An unequal situation consequently continues, where people who are caught up in this system are judged by professionals on their abilities or 'competences', whilst being encouraged to express needs and 'become' independent. It is also a position that fails to recognize the diversity between people labelled as having learning difficulties. This is particularly evident for women, where issues concerning gendered differences continue to be unrecognized and relatively low on the agenda of service provision (Clements 1995; Brown 1996; Scior 2003). In view of this situation, this investigation set out to record some of these life experiences, or what Goodley (2000) calls the 'lives that exist beyond the label'. Rather than relating to a label that has been constructed through medical and welfare discourses, I wanted to know how women themselves told their own stories, and understood their lives, as opposed to the case histories recorded by others including carers, families and professionals. However, what soon became clear in this study were the relationships and the intrinsic power dynamics that existed between the women and caring professionals.

Challenging behaviour?
For many of the women included in the research there was little doubt that certain aspects of government policies, community care plans and the more recent policy for direct payments had indeed improved their lives. On a political front, the success of self-advocacy groups and organisations like People First promoted a sense of solidarity and self empowerment. Yet relations with social workers, care managers and staff remained tense. To illustrate some of these dynamics, I return to the narrative of Beccy and also draw on the accounts of Hanna and Jacky.

Beccy has experienced a number of conflicts with care professionals but perhaps the most detrimental experience, in relation to her mental health and well being, has concerned her two children. Both were adopted, although Beccy has been allowed to keep in touch with the 'new' parents. Around her home Beccy has photographs of her children and during the time of my contact she often spoke of her turmoil regarding them. The son, now aged nine had expressed a wish to see his mother. Beccy finds this difficult to cope with as she believes the child will hate her, claiming:

> Why does he want to see me? He must hate me. I left him as a baby, he must know that? But I didn't leave him, Social Services took him, but he's not to know that. It wasn't my idea to have the children adopted. You know, one minute I had 'em and the

next I had a safety order slapped on me.

Beccy has been advised that she can write to her son but the letter should not contain anything emotional and she should not mention her love for him (Beccy asked me 'how' she could write such a letter). Reflecting on her life experiences and the loss of her children, Beccy says: 'I was nothing more than a surrogate mother. I've been used ... to give kids to someone else'.

Beccy's insight into her own situation and how she now feels used by Social Services and other professional agencies, demonstrates a degree of ingenuity that reaches far beyond the deterministic label of learning difficulty. Such understanding is also evident in Hanna's life history. Like Beccy, Hanna also has a deep mistrust of social workers. Hanna quizzed me thoroughly over my role as researcher, convinced I was a social worker in disguise and out to: 'trip me up'. Once reassured, Hanna related a string of events, which illustrated the huge influence that professionals had, and continue to exercise, in her life. She claims she has been 'passed from pillar to post with no respect'. Her life consisted of a series of moves from institutions, residential homes, hostels and day centres. For a period Hanna was homeless and lived on the streets. There were also experiences of sexual abuse and a terminated pregnancy, although Hanna asserts that she was coerced into having an abortion by her parents and doctors. She related how one social worker had later accessed these data in her medical records, without her consent, and used the information in a manner that breached confidentiality. Indeed, during the period of interviewing, Hanna's wrangling with her new social worker became apparent. Often appointments were cancelled at the last minute, leaving Hanna annoyed and disappointed. She may have taken the morning off working in the local pub in order to meet the social worker. The irony is that Hanna is relatively independent, yet remains dependent on the social worker for certain requirements.

In contrast, Hanna has very good relations with the Day Centre manager, the office and care staff. The centre that Hanna attends works on 'social model' principles rather than within a medical model. Emphasis is placed on the removal of disabling social and environmental barriers. The centre, which has evolved into a 'drop-in' point, has established good relations with the local community as well as focusing on employment prospects. Finding suitable housing and the chance to engage in further education is high on the agenda for service users. There is also opportunity to join alternative or complementary therapies

and take courses in health and exercise routines. Hanna does yoga, has a healthy diet, regular exercise and goes for aromatherapy sessions. She says: 'after a "do" with her (social worker) its nice to have a relaxing massage'. In effect, Hanna's decision to seek out such alternative support is part of her resistance to the system she is caught up in with the local Social Services. This is a situation where she feels powerless. On the other hand, her relations with the people in the Day Centre and the chance to exercise her choice in health care do provide a sense of autonomy. Unfortunately, this situation does not apply in all cases.

Jacky, who lives in a very different environment, in another part of the UK, does not have access to many services other than the Day Centre and her 'new' social worker. Unlike Hanna's situation, the Day Centre remains in the rather traditional model of 'caring' for its users as opposed to promoting empowering activities. This pattern had been replicated by Jacky's parents who continued to treat her as the eternal child, even though Jacky is a woman in her mid-thirties. However, the sudden death of her mother placed Jacky unexpectedly in the role of caring for her father. Like the interdependent relationship between Beccy and her father, Jacky's dad strives to maintain her in a manageable, child-like position. This is a position that her mother sustained over the years in her role of carer for Jacky and also carer for her husband. Her death had a profound effect upon them both. Yet the fact that Jacky is taking on more of her mother's role in the home increases her independence but also creates conflict with her father.

This is further complicated by her desire to form a more permanent relationship with her boyfriend Terry, although her father is unprepared to accept such an arrangement. The extra support Jacky and her dad requested resulted in Jacky being placed in weekend respite care, in order to give her father a 'break'. Jacky was outraged by this and claimed that 'me and dad just need a bit of help in the house and someone to talk to'. She feels that the social worker brought in to assist the situation is actually 'interfering not helping'. Jacky did indeed spend time in a range of respite care units and spent the whole time worrying about her father, who requires practical assistance in the home. However, with careful planning, Jacky managed to turn these events to her and her boyfriend's advantage. They realised that by careful negotiation they could arrange to spend the weekend in the same respite care unit, and thus see each other in relative privacy. Both Jacky and her boyfriend understood this liaison and the clandestine planning involved as a rebellious act against those in control of their lives, but also a situation they were forced into.

These brief snapshot accounts provide some insight into the disturbance women experience in their day-to-day lives with professionals and service provision. Conflicting opinions and drastic interventions made by professionals, particularly concerning parenting and sexuality, have been documented by other researchers (for example, McCarthy 1999; Boxall, Jones and Smith 2003; Olsen and Clarke 2003). Participants in this study spoke of these conflicting opinions and the attitudinal barriers professionals present that further compound the social and environmental barriers they also face. Beccy, for example, spoke at length about the disapproving attitudes she encountered, not only with health and welfare professionals, but also to a certain extent with her neighbours. The fact that she is a disabled woman and a mother appears problematic, even threatening. Beccy concluded her account by stating that 'now I've had the hysterectomy...they might get off me back'.

With all the professional advice Beccy has received over the years there seems little evidence of appropriate emotional support. Beccy's experience of grief and loss, which accumulates as a mental health 'disorder', seems to have gone unnoticed. Instead, Beccy, like Hanna and Jacky, are considered to exhibit 'challenging behaviour'. In Jacky's case her 'behaviour' emerged from the failure of service provision and social workers to understand and recognise the period of transition she was undergoing. A reworking of these power dynamics and the controlling interventions made by professionals would indeed raise the question of 'whose behaviour was challenging?' However, the narratives also exposed another area where participants encountered problems in daily life. This concerned the right to be in control of their own bodies.

Bodily integrity
Bodily integrity is a term borrowed from Williams (1999: 680), who uses it to define the 'right of the individual to protect his/her body against external or internal risk'. This right is considered the fundamental factor in the sustenance of the autonomous welfare subject. Here, I use the term to describe how women claimed their right to control their own bodies and to protect themselves, and others, from risk. Part of this risk stemmed from the need to maintain their personal health as well as to be safeguarded from the threat of physical or sexual abuse. This 'bodily integrity' is also applied to negotiate the constraints experienced within service provision. For example, it has been described how Jacky expressed her bodily integrity by exercising her right to engage in a relationship with Terry. By manipulating their circumstances, Jacky

managed to meet Terry while they we both 'in care' in respite units. Although Jacky may be victim of an oppressive system, she also demonstrates the ability to partially disrupt that system. Likewise, Hanna guarded her right to choose alternative methods of healthcare when she favoured aromatherapy as a means to relax, as opposed to prescribed medication. In part, this was an act of resistance against the established 'norms' of traditional medical services, but I would suggest that it was also the desire to maintain control over her body and who had access to it. Hanna, as with the majority of female participants interviewed in this study, had been subjected to sexual and physical abuse in the past. As a result, the possibility of entering into a conventional male / female relationship posed the greatest risk and threat to her bodily integrity. Hanna now claims friendships, as opposed to relationships, are important to her, as well as being in control of her own health and well being.

The question of who has access to bodies, and who makes choices for bodies, was highlighted in the narratives of Yvonne and Shona. Yvonne attends the same day centre as Jacky, and also spends weekends in respite care. Yvonne claims these weekends 'make me ill.' She relates stories of being given her tablets too late, or outside the normal routine, which results in her having a 'do' (epileptic seizure). She also used the word 'disgusted' to describe her bathing experiences in the care unit. Apparently, Yvonne had been left in a bathroom for some time without towels or a bathrobe. This resulted in her getting cold and having to walk naked through a corridor in order to get to her room. The experience had a marked effect on Yvonne, who felt humiliated and reported that staff failed to show respect. Indeed Yvonne's account corresponds with participants in McCarthy's (1999) study, who related similar incidents concerning lack of personal privacy when bathing. Not only did Yvonne feel embarrassed, she felt her body had been neglected by those designated to care for it.

It is also apparent from the participant's accounts how they felt their bodies were contained and policed through a system of institutionalised discourses. On a macro level the structure of educational and welfare provision intersecting with medical and social work practices bears down upon them, recording every action. These pressures filter into the minute activities of day-to-day lives. Case notes, daily logbook accounts, personal programme plans and reviews, all document patterns of behaviour and personal bodily functions. Visits to the doctor or dentist, dates of menstruation, times of baths, personal hygiene recommendations and so on, are all noted down for women who live in

residential care. Many women spoke of their lack of choice concerning dress, or how keyworkers would select clothes on their behalf or recommend a certain style. Shona, for example, reported how her keyworker, who was roughly the same body size as her, would try clothes on in the shop so that Shona could see how they looked, although Shona did not try the clothes on herself until she got home. Shona says that she would like more opportunity to shop and select her own things as she feels she 'looks a bit like her' (the keyworker). Yet despite her lack of choice regarding clothes, Shona states that she gets on well with her keyworker and other staff in the house, and regards her social worker as 'a friend, my advocate'.

The 'turn' to embodiment
As stated earlier, Hanna also gets on with staff members at the Day Centre. In addition, a significant number of other participants also shared common experiences with female care workers. This commonality centred on bodily matters and mainly focused on diets, exercise, health issues - particularly the menopause, and clothes. Many of the participants were members of women's groups that had been organised by female support workers. From my attendance and observations made during some of these sessions, plus the accounts provided by other participants and support workers, it was evident that the desire for 'bodily integrity' also applied to female staff. The attention to bodily matters therefore indicates a move away from the biological / medical model to a more social understanding of the body.

There are a number of factors that have encouraged this shift, although the influence of the disabled people's movement and impact of feminism has accelerated this change (Phillips 2002). As Williams (1999) explains, professional (medical, social work and education) control of the 'body' came under threat during the 1960s when a wide range of campaigns began to resist professional judgements. Many of these campaigns were spearheaded by feminists who sought to reclaim bodies from abusive relationships, rape and sexual violence as well as actively campaigning against ECT (electric convulsion therapy), abortion and reproductive rights. Evident in this study has been the 'filtering down' of these earlier campaigns and the changes they produced. For example, there was recognition and increased awareness of violence and abusive relationships, plus knowledge of campaigns (like Zero Tolerance) and legal procedures to challenge these harmful practices. Additionally, concerns about health and well being were high on the agenda, with a move away from medical or drug intervention to that of alternative practices like aromatherapy, yoga, massage and attention to

diet.

Part of this reconfiguration of social relations includes the notion of an 'embodied identity'. In this context, the body is a channel through which social and cultural meanings are inscribed, and thus a site of identity and knowledge (Bourdieu 1990; Turner 1992). The attention to bodily matters and the 'turn' to complementary medicine, as opposed to allopathic, are part of this transformation. The participants who engaged in these practices experienced a sense of 'embodied agency'; a means of controlling their own body through their choice of methods. In this context, the 'demystification of professional knowledge and techniques' (Williams 1999: 680) presented an opportunity where women, who have been subjected to a range of medical and social controls, can become relatively autonomous. One of the main influences in this shift, in relation to the participants in this study, has been the input from support staff. It was evident that several female care workers possessed knowledge of heath and personal safety issues and extended this information to the women they supported. However, on the negative side, media and cultural representations of the female body also placed importance on body image and dieting, and in some situations this conflicted with bodily integrity. For example, eating disorders, anorexia and self-abuse among women with learning difficulties are areas that deserve greater attention and research.

Obviously, several other factors underpin the above shift and are worthy of inclusion at this stage. First, the impact of community care arrangements that promoted a shift to smaller group homes and then to independent living or shared housing was an important factor in the life-quality of the participants. More recent emphasis on education, and policy drives to encourage inclusion in mainstream further education colleges, were particularly beneficial to the younger women; whereas women like Hanna and Beccy who attended 'special school' now claim 'not to have been educated'. Equally, recent policy changes leading to direct payments assist recipients to make informed choices, and challenge traditional notions of 'care'. For example, organisations like Values Into Action (VIA) provide clear guidelines for people with learning difficulties who wish to access the Direct Payment scheme in order to buy and manage their own personal assistants. Williams (1999, 2001) also highlights the influence of local self-help and support groups, as well large-scale organisations like the British Council of Disabled People (BCODP) and People First, who have not only provided greater access to information but also challenge assumptions of dependency and medical labelling. Additionally, the demands of these groups to have a

say in the organisation of services and to be recognised and respected for their differences have 'raised important questions about the social relations of the organisation and delivery of care services' (Williams 2001: 471).

Review
This chapter has sought to explore the impact of professional health and social care systems in the daily lives of women labelled as having learning difficulties. From the brief narrative accounts it is evident that dynamics of power relations between women and these networks of care are somewhat strained. Running parallel to these practices however, is evidence of health and support needs being met, albeit not through traditional medical services or professional agencies. As stated previously, the demystification of these professional knowledges and techniques has, in turn, produced strong alliances between female support staff and the women they support. Thus the emergence of a 'social body' as opposed to a 'medicalised body' has created an opportunity for women to exercise their bodily integrity. These shifts of power relations, I suggest, are evident in comparatively small, yet significant changes in non-medicalised, alternative health practices, as well as through a social model understanding of learning difficulties.

Earlier, this chapter referred to New Labour's ideology on social care, particularly the significance of 'partnerships' and 'inclusion'. The issue of 'partnerships' remains a contentious and controversial area of debate. Even though some professionals may feel undermined, my argument and indeed the narrative voices in this research project, illustrate that 'real' partnerships between people with learning difficulties and professionals are not being made. It appears that although some 'hands-on' support staff have embraced and promoted positive attitudes, these changes are not visible on a higher professional level. This is perhaps most obvious in the failure of professionals to recognise people with learning difficulties in a holistic context. Life style adjustments, periods of transition and issues concerning parenting and sexuality are all areas that require greater understanding. These understandings will not come about while professionals continue to relate to learning difficulties as a purely medical / behavioural condition. This approach not only fails to listen to people with learning difficulties themselves, but also excludes the potential for professionals to seek awareness in alternative directions. Meanwhile, the dilemma is further extended by recent government initiatives based on 'evidence-based' practice (participatory and user-led research) and how this can influence policy and public services (Beresford 2003b). Although this may be an innovative proposal

it could prove difficult to facilitate when professionals are still locked in medical discourses and where the policing of bodies still prevails.

Bibliography

Aspis, S. 1997: Self Advocacy for People with Learning Difficulties. *Disability and Society*, 12 (4), 647-654. Aspis, S. 1999: What they don't tell people with learning difficulties. In M. Corker and S. French (eds), *Disability Discourse*. Buckingham Open University Press. Atkinson, D. 1997: *An Auto/Biographical Approach to Learning Difficulty Research*. Aldershot: Ashgate.

Barnes, C. 1991: *Disabled People in Britain and Discrimination: A case for Anti-Discrimination Legislation*. London: Hurst and Co / BCODP.

Beresford, P. 2003a: Fully Engaged. *Community Care*, 1498, November, 38-41.

Beresford, P. 2003b: *It's Our Lives: A Short Theory of Knowledge, Distance and Experience*. London: Citizen Press & Shaping Our Lives National Users Network.

Blair, T. 1997: Why we must help those excluded from society. *The Independent*, 8th December 2002. Blair, T. 1999: Speech to the Institute for Public Policy Research. London, 14th January 2003. Bourdieu, P. 1990: *The Logic of Practice*. (trans. R. Nice), London: Routledge.

Boxall, K., Jones, M. and Smith, S. 2003: Advocacy and parents with learning difficulties: even when you've got an advocate Social Services still always do what's easiest for them. In D. Race (ed.), *Learning Disability – A Social Approach*. London: Routledge.

Brown, H. 1996: Ordinary women: Issues for women with learning disabilities. *British Journal of Learning Disabilities,* 24 (4), 47-51.

Clements, J. 1995: Real Men, Real Woman, Real Lives? Gender issues in learning disabilities and challenging behaviour. *Disability and Society*, 10 (4), 425-35.

Davis, C. A. 1998: Constructing other selves: (in)competences and the category of learning difficulties. In R. Jenkins (ed.), *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge: Cambridge University Press.

Department of Health 1998: *Modernising Social Services: Promoting Independence, Improving Protection, Raising Standards*. Cm 4169. London: HMSO.

Department of Health/ Home Office 2000: *No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*. London: HMSO.

Department of Health 2001: *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: HMSO.

Dowse, L. 2000: Contesting Practices, Challenging Codes: self-advocacy, disability politics and the social model. *Disability and Society*, 16 (1), 123-141.

Dumbleton, P. 1998: Words and Numbers. *British Journal of Learning Disabilities*, 26 (4), 151-153.

Gilman, M., Swain, J. and Heyman, B. 1997: Life Histories or Case History: the objectification of people with learning difficulties through the tyranny of professional discourse. *Disability and Society*, 12 (3), 254-294.

Goodley, D. 2000: *Self-Advocacy in the Lives of People with Learning Difficulties: the politics of resilience*. Buckingham: Open University Press.

Hattersley, G.P. (ed.) 1987: *People with Mental Handicap: perspectives in intellectual disability*. London: Faber and Faber.

Jenkins, R. (ed.) 1998: *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge: Cambridge University Press.

Jordan, B. 2001: Tough Love: social work, social exclusion and the third way. *British Journal of Social Work*, 31, 527-546.

Leason, K. 2003: Who gets to Decide? *Community Care*, 1481, July, 28 30. McCarthy, M. 1999: *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley Publishers.

Oliver, M. 1996: *Understanding Disability: from theory to practice*, Basingstoke: Macmillan

Olsen, R. and Clarke, H. 2003: *Parenting and Disability: Disabled parents' experiences of raising children*. Bristol: Policy Press.

Phillips, D. 2002: Women, Learning Difficulties and Identity: a study through personal narratives. Unpublished PhD, University of Leeds.

Race, D. 2003a: Cinderella in the Lion's Den – reflections on the place of learning disability in Disability Studies. Paper presented at *Disability Studies: Theory, Policy and Practice* Conference, Lancaster University, 4-6th September.

Race, D. (ed.) 2003b: *Learning Disability – A Social Approach*. London: Routledge.

Ramcharan, P., Roberts, G., Grant, G. and Borland, J. (eds.) 1997: *Empowerment in Everyday Life: Learning Disabilities*. London: Jessica Kingsley.

Ryan, J. and Thomas, F. 1980: *The Politics of Mental Handicap*. London: Free Association Books.

Scior, K. 2003: Using Discourse Analysis to Study the Experiences of Women with Learning Disabilities. *Disability and Society*, 18 (6), 779-795.

Simpson, M. 1999: Bodies, brains, behaviour: the return of the three stooges in learning disability. In M. Corker and S. French (eds.)

Disability Discourse. Buckingham: Open University Press.

Turner, B. 1992: ***Regulating Bodies: Essays in Medical Sociology***. London: Routledge.

Walmsley, J. 1994: Gender, Caring and Learning Disability. Unpublished PhD thesis. Milton Keynes: Open University.

Williams, F. 1999: Good-enough Principles for Welfare. ***Journal of Social Policy,*** 28 (4), 667-687.

Williams, F. 2001: In and beyond New Labour: towards a new political ethics of care. ***Critical Social Policy***, 21 (4), 467-493.