

**THE RELATIONSHIP BETWEEN DISABLED PEOPLE
AND HEALTH AND WELFARE PROFESSIONALS**

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Introduction

This chapter will examine the development of the relationship between disabled people and professionals in the later half of the twentieth century from the perspectives of both professionals and disabled people. The growth of the ideologies and organization of professionals is crucial to the social and historical context in which disability has been constructed in western societies. We will trace the development of power structures and relations within the medical and social professions and the production of disability through institutional discrimination. Central to this analysis will be the role of professionalization and discourses of needs and assessment in the enforced dependency of disabled people and the pervasive ideology of normality. This will provide the basis for a critical analysis of the development of professional models of

professional expertise, professional-client partnerships and consumer-led services.

The development of professional-disabled people relations will also be examined from the viewpoint of disabled people. In particular, we will discuss the growth of the Disabled People's Movement and the establishment of the social model of disability in the reconstruction of power relations and structures in professional-disabled people relations. The emergence and redefinition of disability as a civil rights issue has underpinned fundamental challenges to professional ideologies and models. Particularly significant has been the establishment of Centres for Independent Living and the provision of services for disabled people by disabled people. The increasing popularity of 'direct payment' for disabled people, buying and organizing their own care, will also be discussed.

All such analyses are necessarily circumscribed, and we develop a particular focus in a number of ways. First, we take a particular orientation towards defining disability, that is as a form of oppression and institutionalised discrimination. The social model of disability has historical roots in political action and struggles by disabled people in America (Zola,), Britain and

elsewhere (Barnes, Mercer and Shakespeare, 1999). Second, we concentrate on specific examples of the emergence and manifestations of disabled people's relations with professionals in Britain. In doing so, we recognise that there are clear differences between states, for instance in terms of the general policy context of such relations. Drake (1999) suggests that it is possible to recognise different models of policy in different countries, including: the *laissez-faire* (or minimalist) model; the maximal welfare approach; a hybrid welfare/civil right approach; the right-based policy model, as exemplified by the United States of America; and the piecemeal approach in the United Kingdom. We would argue, however, that the general issues which generate, and are generated by, unequal power relation between disabled people and professionals are relevant notwithstanding policy differences. Third, the analysis is informed by qualitative research, particularly studies of the views and experiences of disabled people. Throughout the chapter we shall illustrate the discussion by drawing on a number of qualitative research projects that we have conducted. These include a case study of institutional discrimination in professional services; a case study of services provided by disabled people themselves; and a study of the views and experiences of disabled professionals.

This analysis of professional-disabled people relations, then, examines the social and historical struggles in the construction of disability and the control of professional services. The aim of the chapter is to examine the relationship as constructed in the dialectic between professionals and disabled people. Critical questions can no longer focus on professionals, their skills, expertise, and interventions for “cure or care”. The possibilities for moving forward are generated within changing power structures and relations between disabled people and professionals.

The Development of Professional Power

The relationship between disabled people and health and welfare professionals has never been an easy one, and an analysis of the relationship needs to take account of a broad and complex context. The relationship cannot be understood without reference to: the social and historical development of professions; the structural elements and, particularly hierarchical nature of professions; the relationship between the state, professionals and disabled people; the relationship among different professional groups; and the ideologies and discourses which underpin professionalism and professional-disabled people relations. The picture becomes even more complex if account is given to differences in the development, structures and ideologies of

different professions, such as those between physiotherapists and social workers, and differences among groups of disabled people, including disabled people from Black and ethnic minority communities.

Notwithstanding the complexity of this context, notions of power have underpinned analyses of professional-disabled people relations and their social and historical context. Though he largely omits disability from his analysis, concentrating rather on gender and racism, Hugman states:

Social power is an integral aspect of the daily working lives of professionals. The centrality of power in professional work has been increasingly recognized . . . (1991: 1)

Focusing specifically on disability, French takes hierarchical power relations as her starting point:

. . . it is an unequal relationship with the professionals holding most of the power. Traditionally professional workers have defined, planned and delivered the services, while disabled people have been passive recipients with little if any opportunity to exercise control. (1994: 103)

In this section, then, we shall outline possible elements in this unequal relationship and trace these within the history of health

and welfare provision for disabled people. In general terms, three associated elements of professional power can be analyzed within professional-disabled people relations, each justified and constructed within ideologies of professionalism (Harrison and Pollitt, 1994). The first concerns the power of individual professionals to assess disabled people, define their problems and needs, specify solutions in terms of interventions, and evaluate the effectiveness of solutions. In McKnight's analysis of professional services, he states:

. . . we see the professions developing internal logistics and public marketing systems that assure use of tools and techniques by assuming that the client doesn't understand what he (sic) needs. Therefore, if the client is to have the benefit of the professional remedy, he must also understand that the professional not only knows what he needs but also how the need is to be met. (1981: 83)

Professional dominance can be seen in assessment procedures where, for example, the therapist's or nurse's observations may be viewed as objective whereas the patient's perceptions are viewed as subjective (Coates and King, 1982), and where pseudo-scientific language serves to mystify and confuse service users (Grieve, 1988; French, 1993). Because of the specialization of the

various professional groups, definitions of need tend to be narrow, their scope being dictated by specialized knowledge and interests (Ellis, 1993). The needs of disabled people, on the other hand, tend to be multifaceted. As Marsh and Fisher point out:

If the process of assessment becomes one of professional discovery of 'need', rather than a negotiation of problems, then users tend to feel hemmed in by the definitions used to describe their circumstances and trapped by the choices they are faced with. (1992: 50)

The second aspect of power involves professionals as powerful groups within society essentially in pursuit of self interest, with the mystification, defining and control of expertise, for instance. This is seen in the establishment of occupations as professions controlling, quintessentially, the qualifications and credentials which define who is and who is not a nurse, physiotherapist or other professional. As Hugman points out, this also serves as a "basis for defining the boundaries of the profession with other professions, and it provides the foundations for power exercised by the professionals in relation to the users of their services." (1991: 83) Davis, a disabled writer and activist, traces professional self-interest to its most basic roots:

It is a well-established form of parasitism, resting on bits of biblical dogma such as 'the poor always ye have with you' (John, xii. 8). The updated version of the old Poor Law, which sustains most of today's welfare professionals, depends for its continuity on such counsels of despair. It has become, let's face it, a nice little earner. (1993: 199)

The third aspect of professional power is as the agents or representatives of the state, or as in some models (Illich, 1976) the economic and political elite. Of particular importance to professional-disabled people relations is the maintenance of the status quo by the pathologizing and individualizing of problems that have been socially and economically created. Oliver and Sapey (1999) develop a model of the relations between the state, professionals and disabled people with particular reference to social work, though it can be generalized to all health and welfare professions. In this model professions stand between the state and disabled people, acting as agents of the state, particularly as arbiters of need. Needs are defined within an individualized (medical, tragic) model which asserts the expertise and professionalism of the professions (Wilding, 1982).

The growth of professional power in relation to disabled people, in each of the three aspects, has been traced, by a number of writers, particularly to the changing nature of work and the associated mass segregation of disabled people in industrial nations in the nineteenth century (Ryan and Thomas, 1987; Oliver, 1990; Finkelstein, 1991; French, 1994a). The segregation of disabled people into specific institutions was influenced by the growing medical profession which tended to view disabled people in terms of their individual impairments. Segregation and institutionalization created dependency and facilitated the development of the medical profession and a whole range of new professions, most of which were dominated by medicine. The domination of the medical profession in professional-disabled people relations contributed to the segregation of, and discrimination against, disabled people and produced arguments, usually biological in nature, to justify the exclusion of disabled people from mainstream social and economic life. This growth of professional power, particularly of the medical profession, in the lives of disabled people led to the medicalization of many areas of disabled people's lives. Doctors became involved in decisions and assessment procedures which had little to do with medicine, such as housing, education and employment.

Any brief summary of professional power in relation to disabled people needs to recognize the complexity and often contradictory nature of professional-disabled people relationships. The medicalization of disability has produced some positive effects, including increased survival rates and increased life expectancy for some disabled people. For instance, one of the authors of this chapter has insulin-dependent Diabetes and would not have survived without medical intervention. Furthermore, as French (1994b) suggests, most people would agree that it is sensible to strengthen muscles, move joints, and assist a person's balance following a spinal cord injury. Nevertheless, the medical profession has taken undue credit for the reduction of both disease and impairment. McKeown (1979) and Sagan (1987) provide a great deal of evidence to show that economic and social development, for example improved housing and diet, purification of water and the efficient disposal of sewage, was far more important than medicine in reducing the incidence of infectious diseases such as poliomyelitis. It is still the case today that most disease and impairment can be found amongst those with limited material resources (Benezeval et. al., 1995) and the majority of "accidents" also occur within this group (Jacobson et. al., 1991). Furthermore, professional power has played a crucial role in the

maintenance and justification of the individual model of disability and the enforced dependency of disabled people. Oliver argues that there are a number of ways in which dependency is created through the delivery of professional services:

The kinds of services that are available - notably residential and day care facilities with their institutionalized regimes, their failure to involve disabled people meaningfully in the running of such facilities, the transportation of users in specialized transport and the rigidity of the routine activities which take place therein - all serve to institutionalize disabled people and create dependency. (1993: 54)

This notion of enforced dependency is a recurring theme in the accounts by disabled people of their experiences with health and welfare services. Slack writes:

The creation of dependency . . . has little to do with choice and much to do with how structures are organized. Disabled people variously become 'clients', 'patients' or 'service users'. They are then filed on computer (permission for this practice is rarely sought), and they 'belong' to that department. (1999: 34)

Specifically in terms of professional-disabled people relationships, Oliver argues that the creation of dependency is two-way. Professionals are also dependent on disabled people for their jobs, salaries, status, quality of life, and so on. Furthermore the construction of disability within the medical model has been contingent upon the expanding production of medical and rehabilitative services: 'The social meanings given to impairment and disability shape public and institutional responses to these conditions and lay the foundation for the construction of a rehabilitation industry' (Albrecht, 1992: 67). The power of professionals in controlling language, knowledge and the social response to disability has defined professional-disabled people relations. It has also contributed to the dominant individual definition of disability, defined the identity of disabled people as service-users and, as discussed below, dominated the daily lives and experiences of many disabled people. It is in this light that Barnes judges rehabilitation services as 'highly discriminatory' and 'a major disservice to disabled people.' (1991: 132) He states:

. . . with the removal of the economic and social barriers which confront disabled people, the need for rehabilitation in its present form would be greatly reduced or eliminated altogether. (1991: 132)

In general terms this basic analysis of the relationship between professionals and disabled people applies throughout the West, notwithstanding significant differences in the detail of their expression in difference cultures. It seems, too, that there are similar issues in developing countries. Coleridge, for instance, suggests that professional training in developing countries tends to follow Western models and Western funding for disability projects is 'directed at the medical model run by professionals wedded to it' (1993: 73). Sanders (1985) states that the cost of construction of one teaching hospital in Zambia could have been used to build 250 health centres in the countryside where most people live. He concludes that their own traditional practices and practitioners have been discredited by the import of Western medicine.

Professional Power: Disabled People's Experiences

The evidence from research and the writings and recollections of disabled people suggests that professional-disabled people relationships are varied but can be experienced as dehumanizing and abusive by disabled people. Straughair and Fawcitt (1992) report that the young people with arthritis they interviewed were sometimes accused of being neurotic when their symptoms did not fit into neat diagnostic slots. Wendell (1996) refers to the power of

professionals to undermine people's beliefs in the reality of their bodily experiences as 'epistemic invalidation'. Doubt can be cast on immediate experiences unless they are confirmed by authorized medical descriptions. One example she gives is of Gloria Murphy (from the work of Register, 1987) who experienced acute dizziness, numbness in her legs, inability to walk at times, double vision, bladder, kidney and bowel problems.

During most of the five years between the onset of her symptoms and her receiving a diagnosis of multiple sclerosis, she was told . . . that she had "housewife's syndrome" and needed only to get busy and to get away from her children to feel better. (Wendell, 1996: 124)

A further example she gives concerns the experiences of a small percentage of people with advanced multiple sclerosis who experience severe pain in their bones, muscles or skin.

Until recent studies confirmed that the disease processes of MS could indeed cause this pain, patients were told that the pain they reported was impossible (James 1993: 241).
(Wendell, 1996: 125)

Lonsdale (1990), reporting her interviews with disabled women, relates many harmful experiences of hospital treatment

and medical care. This particularly concerned doctors who, despite their white coats and other medical trappings, were often perceived by the women as being nothing more than ‘groups of anonymous men’ (1990: 89) An issue which they repeatedly raised was how frightening they had found their hospital experiences, especially as children. They could recall being asked very personal questions in an insensitive way, of being photographed unclothed, and of being compelled to walk naked in front of medical students.

This ‘public stripping’, which is now recognized as a form of institutional abuse, was also experienced by Merry, a disabled woman interviewed by Sutherland. She recalls, ‘ . . . they paraded me up and down on the stage, and the surgeon was saying “who can say what’s wrong with this young lady?”’ (1981: 124).

Michlene, another disabled woman interviewed by Sutherland, has similar unpleasant recollections. She states:

My memory is basically of a whole series of experiences of being very coldly and formally mauled around. It’s very alienating. It’s as if you’re a medical specimen. . . I was never told that I was nice to look at or nice to touch, there was never any feeling of being nice, just of being odd, peculiar. It’s

horrible. It's taken me years and years to get over it. (1981: 123)

Lonsdale (1990) points out that incidents such as these were recalled by women of all ages and so cannot be dismissed as belonging to 'the bad old days'. Coleridge (1993) believes that the self-image of many disabled people has been damaged by constant involvement with professionals particularly during childhood where play, enjoyment, and discovery were replaced by stress, medical examinations, and developmental programmes. He quotes Joshua Malinga, the Secretary General of the Southern Africa Federation of the Disabled:

The point is that they believe that they have solutions to our problems. They do not see us as belonging to society, they think we belong to them, they have to keep files on us throughout our lives, and decide when we should see a doctor and so on. (1993: 74)

Whilst this seems to convey experiences shared by many disabled people, 'damaged self-image' does not seem to be a necessary consequence. Nasa Begum, for instance, is a black disabled activist and is 'involved in the struggles and celebrations of many

movements' (Keith, 1994: 216). She writes of her experiences of regular sessions of physiotherapy during her childhood:

I couldn't see the point of all these agonizing exercises. I was never very good at accepting the fact that things I didn't like could be "good for me" and the physiotherapist managed to do a really good job of making me a conscientious objector for the rest of my life. (Begum, 1994: 48)

Four disabled people, interviewed by Johnson (1993), who had received physiotherapy had similar experiences to those of Begum, and largely dismissed physiotherapy as having no importance in their lives. Such dismissal is not easy in unequal relationships. Ellis (1993) found that people with knowledge of their entitlements were frequently viewed as 'grabbing', demanding or fussy. Practitioners preferred disabled people who accepted with gratitude what was on offer, and described those who challenged this as manipulative.

Morris interviewed women with spinal cord injuries. Their most common complaint about health and welfare professionals was their lack of concern with emotional issues. One woman said, 'There is no space allowed for us to express our grief . . . There is often pressure put on us to "cope" and if we fail to live up to the

standard demanded of us we are categorized as a “problem” (1989: 24). They reported receiving little or no help in coming to terms with paralysis, and often felt compelled to be jolly and play a particular role: as one woman put it, ‘. . . the staff expected you to have a smile on your face all the time’ (1989: 24). Some women experienced a need for counselling, and said that the only thing that made life bearable for them in hospital was their relationships with other patients. Many of the women believed that the rehabilitation they received was unnecessarily competitive, sport-orientated, and geared towards men. Others thought there was too much emphasis on walking and bladder training. Morris states that the majority of women:

. . . found that communication of the vital information about paralysis was poor, that their emotional experience was ignored, that their needs as women were not addressed, and finally they were given little help in planning for the future.

This experience seemed to be as common in the 1980s, as it was during the 1950s, 1960s and 1970s. (1989: 33)

Boazman had mixed responses from health professionals when she became aphasic following a brain haemorrhage:

Their responses towards me varied greatly, some showed great compassion, while others showed complete indifference. I had no way of communicating the fact that I was a bright, intelligent, whole human being. That is what hurt the most.

(1999: 18-19)

Similar mixed experiences were reported by people with aphasia interviewed by Parr and Byng. One person, talking of doctors, said:

. . . when you can't communicate they treat you like a kid and that is just so frustrating - A handful of doctors were just awful. You just wanted to say, 'Do you know what this is like?'

(1997: 74)

Begum (1996) reports many similar themes to those discussed above from her study of disabled women's experiences of general practitioners, though there seemed to be greater variation in experiences than in studies undertaken in institutions such as hospitals. This research was done by a postal questionnaire, and a total of 80 were completed and returned. She found, for instance, examples of GPs refusing to believe physical symptoms:

If I don't get well they say it's psychological (hypochondria, etc.). If it's psychological it's not real/"genuine" (apparently). If it's not real, it doesn't need treatment. If it doesn't need treatment, it's a sign I just need to "pull myself together".
(1996: 186)

Begum (1996) takes institutional discrimination as her basic for analyzing difficulties in the relationship between disabled women and their GPs. Her framework of physical, communication and attitudinal barriers is similar to the analysis adopted for the *Case Study* in the next section of this chapter. Begum found that such barriers deny opportunities to people with impairments and can impede access to the services women require. Disabled women, for instance, often find that information is withheld from them. One of her respondents explained that she hadn't been told that multiple sclerosis had been diagnosed, yet her husband had been told two years before she was informed. It seems too that the flow of information from disabled people to doctors is liable to distortion and failures. This is, at least in part, due to GPs' responses to impairment. One respondent in the research wrote: 'Sometimes I find that a GP - particularly one who is only here for a short time and fairly new - is more interested in my sight

problem, or my child's sight problem, than in what I've come to ask about' (1996: 183-4).

A Case Study: A GP PRACTICE

This case study is based upon a group interview with four members of staff at a GP practice in the north of England. It takes institutional discrimination as the framework for analysis:

Unfair or unequal treatment of individuals or groups which is built into institutional organisations, policies and practices at personal, environmental and structural levels. (Swain et. al., 1998)

The notion of institutional discrimination has played an important role in the development of theories of disability. It is also a notion that links the experiences of people from minority or oppressed groups together (Thompson, 1997). Disabled people face institutional discrimination in a social and physical world that is geared by and for non-disabled people. This prevents their full access to and participation within organizations and within society. Institutional discrimination can be understood in terms of attitudinal, environmental and structural barriers. Attitudinal barriers are constructed on environmental barriers which, in turn, are founded on structural barriers. Essential to understanding

discrimination as being institutionalized is to reject individualized, or victim blaming explanations of unjust treatment.

The GP practice is housed in a building which was erected in the early 1990s. The building contains various physical features which are essential to disabled people, for example an adapted toilet and automatic doors, but many limitations were highlighted. There is no lift to the upper floor, for example, and, although this does not affect patients and clients, it precludes the employment of disabled staff, who cannot manage the stairs, and disabled colleagues from other institutions. Pauline, the health visitor, recalled:

We once had a lady from the Community Health Council.

She was in a wheelchair and she couldn't get up here. So disabled professionals are stuck I think.

No disabled staff are, or have been, employed in the practice.

The fire doors also create a problem. Tom, the GP, explained:

One thing we've got fire doors on the consulting rooms which are quite heavy and that's quite difficult for people. I mean not just people in wheelchairs but people who are frail and elderly. But I don't think there's any way round that.

Many of the disabling features of the building adversely affect non-disabled patients and staff as well. Evelyn, the receptionist, explained:

The reception isn't very good even for able-bodied people because the desks are at a terrible height, with them standing on one side and us sitting on the other. There is a lower area for people who are in wheelchairs but it's completely out of the way, in the wrong place.....so it doesn't get used. Also, it's a very noisy area and it's not very good for confidentiality.

The height of the couches also pose a problem. Angela, the practice nurse, said:

The difficulty that I have is if someone has to get from a wheelchair to a high couch, that it quite difficult for them because I'm usually working by myself.....If they've got someone with them, a carer, they'll come in and help because they know how the person likes to be moved and what they can do.

The high couches also pose a problem for Tom and his patients and changes the way he works:

I think the difficulty is, people in wheelchairs particularly, unless there's a good reason we tend not to examine them on

the couch. This is not necessarily the best thing but it is the most practical thing really.

These problems could be solved, in part, by having adjustable couches.

The building also poses problems for disabled parents with young children. Pauline explained:

We have a problem in the clinic area. I can think of one lady who has a disability with a young child and all of our changing mats are up at a height, the scales are on a table, it's all designed for able-bodied people. She has great problems lifting the baby, she has to bring a relative in to give her a hand.

The staff have available to them a list of interpreters to assist communication with deaf people and Pauline and Evelyn have both attended evening classes to learn sign language which they financed themselves. Unfortunately they do not get sufficient practice. Evelyn said:

Anyone who came in who was deaf I used to say "Do you sign?" and they would say "No". Then last week this deaf chap came in and I said "Do you sign?" and he said "Yes" and

he started to sign away at me and I said “Stop, I've forgotten it all.”

Angela highlighted particular ways in which deaf people might be denied full access to the service:

You might not pick up on the cues you get from people who are hearing. You know, how they come in with a sore throat and they want to talk about their marriage or whatever it is.

With someone who is profoundly deaf you would just treat the sore throat.....You wouldn't pick up the subtleties.

Very little adaptation is made in the practice for visually disabled people though the practice leaflet has been transcribed into braille.

Angela mentioned the hazards of the car parking area:

It's horrendous. If blind people are using a stick there is nothing to guide them across from the pavement. There's a small path but they've still got to get over the car parking area and cars are always coming and going. And there's the bollards.

People with learning difficulties are seen in the practice but no specific provision is made for them. Tom said that no service would be knowingly denied and that every person would be treated as an individual. There is a Community Learning Disability Team in the area and Angela, talking of routine health checks, felt that it

might be better if people with learning difficulties received such services from the specialist team:

Personally I would find it quite difficult. I mean people who are trained in dealing with learning disability they know exactly what level to pitch their communication. I find that quite hard to do. They were suggesting a nurse to do smears, blood pressure and things like that, but if we've got a Community Learning Disability Team who are specialists, why not use them but perhaps bring them into the practice if we've got a room available.

Looked at in terms of institutional discrimination, this GP practice has numerous disabling features which preclude many disabled people from working there and causes great difficulty for disabled patients and clients as well as the staff themselves, although it was built in the 1990s. The building was designed without any consultation with the staff or with disabled people. Angela thinks it meets legal requirements but no more.

Some of the adaptations that have been made are useful but they can be regarded, overall, as tokenistic. An example of this is the single leaflet translated into braille. The practice has many other leaflets, regarding health education, which are not accessible

to many visually disabled people or people with learning difficulties. There is no information in large print or on audiotape even though only a fraction of visually disabled people read braille. Evelyn said, 'I've found this out - like most deaf people don't sign.' This illustrates many environmental barriers in institutional discrimination.

Several examples of structural discrimination arose in this interview. Although the staff in the practice seem keen to provide disabled people with a quality service, they have not had the opportunity to attend Disability Equality Training and are forced to rely on 'intuition' and 'common sense'. Evelyn said:

We do a lot of training but we've never done that kind of training. I think the girls are very intuitive, most of them have been in the job a long time, they're very good about picking up on people who can't read, for example, or filling in their forms. It (disability equality training) has never come up and I've been here for fifteen years. It's long over-due.

There is no user involvement in the management and running of the practice. Tom tentatively justified this in terms of the non-representation of people who join committees:

It has been muted obviously but we decided it wasn't really.....I don't know how to put it.....They're not representative of the population really, the usual sort of thing, the same sort of patients all the time.

This argument for the exclusion of disabled people has been strongly rejected by disabled people. Oliver states:

In representative democracies, representation is always less than perfect, the Conservative Party does not represent all Conservative voters, nor does the British Medical Association represent all doctors.....And yet the right of the Disability Movement to represent disabled people is continually questioned by politicians, policy makers and professionals alike.....If the legitimate claims of the movement to represent disabled people is denied, who else will represent our interest - doctors, politicians, the Royal Institutes and Associations?
(1996:150)

The issue of how far people with learning difficulties should be in mainstream health and social services is also a contentious one. Although there may be some advantages to specialist services, as outlined by Angela, the existence of specialist services has the potential to create feelings of inadequacy and deficiency in other

workers and goes against the philosophy of inclusion of disabled people in society. Sperlinger states:

A significant number of GPs do not feel that they should have the lead responsibility for dealing with general medical problems of people with learning disabilities, but assert that it should be the role of medical staff from the specialist learning disability team.....Studies consistently show that primary health care team members acknowledge that they have only minimal education on the needs of this client group, yet only a minority welcome the possibility of further training. (1997:12)

Treating people at home, as a solution to an inaccessible environment, can also deny disabled people the opportunity to participate fully in society, and treating people 'as individuals', as a substitute for dismantling disabling barriers, is unlikely to bring about equality of service or full accessibility for disabled people.

Disabled Professionals

Disabled professionals stand in an interesting position in an analysis of the relationship between professional and disabled people. Indeed, it can be argued that the acceptance of more than a few disabled people into professions could seriously challenge the traditional professional-disabled people relationship where the

professional is considered to be the expert and occupies a dominant position over the client (French, 1995). The emergence of disabled professionals can be seen as particularly significant for marginalized groups such as Black and ethnic minority Deaf people (Ahmad et. al., 1998). Studies have shown that disabled people are effective as professionals. The American Society of Handicapped Physicians found that approximately 75% of doctors with a wide variety of impairments remain successfully employed in clinical practice (Wainapel and Bernbaum, 1986; Wainapel, 1987). French (1990) in her interviews with physiotherapists found various advantages in being visually impaired, including an increased knowledge of disability, the ability to empathize and the breaking down of professional barriers.

Nevertheless, the available evidence suggests that the power of professionals in relation to disabled people is perpetuated through discrimination against disabled people in entering professions. In our research in the area of social work (French et. al., 1997) we found that disabled people have experienced institutional discrimination when attempting to gain entry to social work training (James and Thomas, 1996; Baron et. al., 1996). Once qualified, some disabled social workers have had to

overcome significant barriers to employment and promotion (French, 1988). Much has been written about the institutionalized racism and sexism that excludes women and black people from the higher echelons of social work management. In contrast very little has been written about the discrimination experienced by disabled professionals. In French et. al. (1997) there is a case study of Alan Dudley who is blind and a senior social worker. The barriers he faced began in gaining access to training when he received ten rejections before he was offered a place on a course. Once qualified he had similar difficulties finding a job. He said:

I was told by many local authorities 'Well if you want to work with blind people we'll offer you a job, but if you don't, we're not prepared to.' I can actually remember crying tears of frustration over this issue.

This is compatible to the findings of French's study of the experiences of disabled health and welfare professionals. She concluded:

A sizable minority.....had experienced some degree of negative discrimination either as a result of their colleagues attitudes or lack of understanding. Most of these problems occurred when attempting to gain access to training and during training. (1988: 584)

Baron et. al. found that there were many disabling barriers to recruitment and training on Diploma in Social Work programmes. They state that, 'A lack of experience of disability issues was evident as well as the absence of an active approach to arrange support at all levels of the programme.....' (1996:175). James and Thomas (1996) undertook a programme to give greater prominence to work with disabled people on a Diploma in Social Work course and to attract more disabled students to social work training. They found that many practice teachers in voluntary and statutory settings were reluctant to recruit disabled students and cited fire regulations, or the fear that they would be vulnerable to violent or aggressive clients as justifications. It is clear that discrimination and oppression occurs, albeit sometimes unintentionally or subconsciously, within professionals' own agencies and is embedded within such everyday practices as student recruitment and training.

Disabled People Power

As we have seen, professional-disabled people relations are unequal and dominated by professionals. However, the danger of such an analysis is that it casts disabled people in a passive role, with no account given to active resistance. In this section we turn

to disabled people power in controlling the provision of services and professional help. Indeed, it can be argued that, with the growth of the Disabled People's Movement, the greatest challenge to professional dominance has come from disabled people themselves.

Since the inception of the welfare state, disabled people have constituted, potentially, a powerful political force, yet because of the widespread discrimination against them, in terms of education, employment, transport, professional power and so on, they have been rendered relatively powerless. This situation has, however, gradually changed, and disabled people have come together to campaign for change and a strong Disabled People's Movement has emerged (Campbell and Oliver, 1996). The movement consists of organizations of disabled people, that is organizations which are controlled by disabled people themselves, although many welcome non-disabled allies. Perhaps the most significant turning point in Britain in the Disabled People's Movement was the formation in 1974 of The Union of Physically Impaired Against Segregation (UPIAS). Davis (1993) explains how UPIAS fought to change the definition of disability from one of individual tragedy to one of social oppression. This paved the way for the development

of the social model of disability. This model has arisen from the experiences of disabled people themselves. It is borne out of the collective experience of disabled people, challenging 'the way they had been defined and controlled by the experts who manipulate disability policy.' (Davis 1993: 289) It is no coincidence that the Disabled People's Movement and the social model of disability have developed together. The social model emanates from the pooled experience and discussion of oppression. As Rachel Hurst of the Disabled People's International states:

When you come together with other disabled people, you have the time and the opportunity to discuss what the situation really is - what oppression is, who is oppressing you; where oppression comes from; what discrimination is and where it comes from. (Coleridge 1993: 54)

The growth of organizations run and controlled by disabled people has taken place in many countries when disabled people come together through choice. Khalfan Khalfan, for example, was inspired to found the *Association of Disabled People of Zanzibar* after meeting disabled people from around the world at a conference in Singapore. On occasions, active associations have stemmed from the dissatisfaction of disabled people living in segregated institutions. This is how the Disabled People's

Movement in Zimbabwe started, now one of the strongest in Africa. In Lebanon the Disabled People's Movement was triggered by the large number of people disabled in the war, and is now the strongest in the Middle East (Coleridge, 1993; French and Swain, 1997).

The political implications of the social model, often explicitly stated, are to promote the collective struggle by disabled people for social change. One measure of the effectiveness of the model has been the proliferation of the Disabled People's Movement and the burgeoning of not only many small organizations throughout the world but also national (e.g. The British Council of Organizations of Disabled People BCOOP, in 1981, now called The British Council of Disabled People) and international (e.g. Disabled People's International, DPI, also in 1981) umbrella organizations, all of which are organized by disabled people. BCOOP continues to expand and now represents some 112 organizations and over 200,000 people, while the DPI represents over 70 national assemblies of disabled people throughout the world.

A large number of BCOOP's member organizations comprise coalitions of disabled people and Centres of Integrated Living.

The philosophy of integrated living, evolving as it has from the social model, and the CILs provide a clear challenge to the dominance of professionals in relation to disabled people. One assumption, for instance, is that 'people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives' (Morris, 1993a: 7). The CILs, which employ many disabled people, gained much of their inspiration and impetus from the Independent Living Movement in the USA which developed in the 1960s and 1970s. There are important differences between CILs in the USA and those in Great Britain. The main difference is that in Great Britain, owing to the existence of the welfare state, CILs work, to a varying extent (Leaman, 1996), in harness with health authorities and local authorities to develop new approaches and to ensure that disabled people receive the support which is their right (French, 1994c). In the USA CILs operate more independently. This difference is reflected in the naming of the centres: they are termed *Integrated* in Great Britain and *Independent* in the USA.

The first CIL was established in Berkeley, California in 1973 and within ten years more than 200 CILs had been established across the USA (Priestley, 1999). Related projects also emerged

in mainland Europe in the 1970s, including the *Fokus* projects in Sweden, *Collectivehaus* initiatives in Denmark and *Het Dorp* in the Netherlands (Brattgard, 1972; Klapwijk, 1981; Zola, 1982). The *Derbyshire Centre for Integrated Living* (DCIL) (the subject of a detailed case study below) was the first to be established in Britain. This is now one of a few examples of organization of disabled people which have successfully provided services which promote independent living (Morris, 1993b). In relation to the power of professions the growth of “consumerism”, self-help and the movement for independent/integrated living can be seen as an emerging counter-tendency (Zola, 1987). Priestley, in his research with DCIL, shows that there are ‘key value differences between the competing policy agendas of British disability policy and the disabled people’s movement are both numerous and complex’ (1999: 77). The first, from an individual tragedy model has been preoccupied with care, medicalization and segregation, while the later, from a social model viewpoint, has promoted participation, inclusion and equality. He argues that where the implementation of community care policies has reinforced professional domination, the exploitation of “informal carers” and the individualization of disability, the disabled people’s movement has advanced values of self-help, communalism and citizenship. For Priestley, the control

of evaluation of services is crucial, and in particular the promotion of life quality issues rather than the technicalities of quality assurance systems. He states:

Quality of life is hard to define and any attempt to do so is inherently value-led. The selection of measurement indicators is not only a technical process but also a political one. For this reason the ability of particular groups to define 'quality', and the value base which they use to do it, will also determine the kinds of services which are thought to have 'value'. (1999: 187)

It can be argued that the diminution of professional power allows disabled people more freedom to organize their own care. The introduction of direct payments to disabled people is one example. Oliver and Zarb (1992) found that disabled people who received direct payment had more freedom to participate in employment and leisure activities of their choice. They could arrange to receive the kind of help they wanted at a time that would fit with their requirements and schedules. The notion that personal assistance should be provided by trained and qualified personnel has also been challenged by disabled people:

I'm not looking for professional qualifications, nurses are definitely out, I'm looking for people who are enthusiastic....I want to train them in my own way. (Morris 1993a:32)

Such flexibility allowed disabled people to follow the lifestyles of their choice. From their research in which 70 disabled people were interviewed, Zarb and Nadash state:

Findings from the research highlight that payments schemes are associated with higher quality support arrangements than direct service provision. In particular, the payments option clearly offers disabled people a greater degree of choice and control, and, consequently, leads to higher user satisfaction. Most importantly, support arrangements which are funded through the payments option are almost invariably more reliable (and, therefore, more efficient) than those supported by direct service provision. (1994, ii)

From his research with the Derbyshire Centre for Integrated Living, however, Priestley (1999) suggests that some disabled people require support in managing their own package of financial support, such as the information, advocacy and peer support provided by organizations of disabled people.

Case Study: DERBYSHIRE CENTRE FOR INTEGRATED LIVING

The Derbyshire Centre for Integrated Living (DCIL) was founded in 1985 as an initiative of the Derbyshire Coalition of Disabled People working in collaboration with Derbyshire County Council. The aim of the DCIL is to secure a full economic, public and social life for disabled people in accordance with their own wishes and desired lifestyles. It exists to find ways of removing barriers which stand in the way of disabled people leading full and satisfying lives. The centre is run jointly by disabled and non-disabled people working in partnership.

The aims of the centre are based upon seven basic needs which have been identified by disabled people themselves. These needs, which all interact and must, therefore, be provided in an integrated way, are for: information; technical aids; transport; counselling; housing; personal assistance; and access.

The DCIL maintains an up-to-date and comprehensive information base for disabled people, their assistants and service providers. It is also available to researchers. This data base of information is extensive including, for example, information on holidays with over 3,000 accessible venues. The first point of

contact for inquirers is with a disabled person who has wide knowledge of disability issues as well as personal experience of disability. A Minicom is provided so that hearing impaired people can use the telephone and the information is also available in braille, large print and on audiotape. A braille, large print and computer consultancy service are available commercially to other agencies.

The DCIL has a team of trained peer counsellors who are mostly disabled themselves. This service provides support for disabled people who are feeling isolated or experiencing difficulties in areas such as sexuality or transition to independence. The counsellors bring their own experience of disability to the situation and are not shocked by sensitive subjects or feelings such as grief and anger. The DCIL also provides training which, though tailored to specific requirements, is based upon a thorough understanding of the social construction of disability. Training is provided for volunteers, counsellors, information workers and local access and transport groups. A range of courses are offered on a commercial basis.

The Derbyshire Centre of Integrated Living provides personal support services and personal assistance. They state:

DCIL supports the right of all disabled people to determine, how, when, where and by whom the services they need are provided. (Derbyshire Centre for Integrated Living: Undateda)

Personal assistance can be defined as help provided by other people to enable disabled people to live the lives they choose. Support may be needed in returning to work, going to college, or coping with rehabilitation or the onset of impairment. Each package of personal assistance is designed to meet the individual wishes and needs of the disabled person and is managed by, or co-managed with, the disabled person him or herself.

The Derbyshire Centre of Integrated Living works in partnership with many other organizations including SCOPE, British Association for Counselling, Living Options Partnership and The Consortium on Opportunities for Volunteering. Its aim is to highlight disabling practices and help develop more appropriate services for disabled people. DCIL participates in joint planning with Health and Social Services ensuring that the personnel of these services understand the priorities of disabled people.

Looked at in terms of institutional discrimination, it appears that many of the barriers disabled people routinely face have been

removed within the organization. The building is accessible to people using wheelchairs, and braille, audiotape and large print are all provided. The people giving information have a broad knowledge of disability issues, not only in a professional sense, but in terms of personal experience. A counselling service is provided by qualified disabled counsellors who have first hand experience of encountering and removing barriers which stand in the way of a fulfilling lifestyle.

The Derbyshire Centre of Integrated Living provides Disability Equality Training to its own staff and volunteers as well as outside agencies. Disability Equality Training, in contrast to Disability Awareness Training, does not focus solely on attitudes but on every aspect of disabling barriers and institutionalized discrimination. This is to ensure that people, such as volunteers, understand the full extent of the barriers which disabled people face and that attitudes are seen within an historical and cultural context.

The staff of DCIL work within the community, not simply to visit and help disabled people overcome problems, but to empower them to bring about changes themselves. DCIL helps disabled people to find appropriate personal assistance, which is

not controlling or patronizing, to enable them to lead the lifestyles of their choice. They state:

In the past many disabled people have had services delivered to them which have not given them sufficient control over their lives, for example services which of necessity have had to conform to particular models of service provision into which disabled people had to fit.....We offer a different approach. Because we believe that disabled people have the right to determine their own lives in every aspect, we offer a service that reflects this approach.
(Derbyshire Centre for Integrated Living: Undatedb)

In his research in Derbyshire, Priestley endorsed the findings of previous studies concerning indicators of process quality important to disabled people: 'increased flexibility, choice, control and reliability which self-management offered them.' (1999: 143) These criteria were apparent in 'outcomes' identified by users of DCIL Personal Support Service. Terry stated:

I can go shopping when I want to. I can go out for a day if I want to, under the restraints that there are . . . and I could only do that sort of thing because I've got people to rely on.
(1999: 174)

When services are provided to disabled people by large bureaucratic organizations unacceptable delays are very common.

Carol states:

. . . they wouldn't let me keep changing my times. . . I felt as if I just couldn't organise my life in any way. I couldn't just say, have a lie in, because I'd got to ring social services just to have a lie in. (Priestley, 1999: 144)

There is often a lack of concern or understanding that disabled people are dependent on equipment, such as a wheelchair, a visual aid or a car, to function adequately at work or to enjoy leisure pursuits. These delays are frequently underpinned by structural discrimination where disabled people are viewed as unimportant or where lack of resources make delays inevitable. The repair and maintenance service at DCIL removes the anxiety and frustration when equipment breaks down and helps disabled people remain active citizens on their own terms.

It is likely, then, that within the culture and ethos of DCIL, attitudes and behaviour towards disabled people is good, illustrating that attitudes are shaped by organizational philosophies and practices. Decision making and working practices within the organization are controlled by disabled people who do not regard

disability as an individualized tragedy but as a civil rights issue.

Every aspect of the work is geared towards the fulfillment of disabled people on their own terms and in viewing disabled people as active, capable citizens who are restricted, not by impairment, but by a disabling society.

Changing Professional-Disabled People Relations

Brisenden writes:

I have a fantasy that in some future world people with disabilities will be able to insist on the right to interrogate doctors, rather than be interrogated by them. In this fantasy, a doctor is placed on stage in front of a large audience of people with disabilities, in order that we may come to understand the stigma of a career in medicine, and the effect this may have on family and friends. . . the feeling of power might prove too irresistible to be ignored. (1998: 22)

Is this pure fantasy or are professional-disabled people relations moving towards a shift of power? In this concluding section, we focus specifically on possibilities for a changing relationship between professionals and disabled people. As throughout the analysis in this chapter, various competing and contradictory factors need to be taken into account, including: the changing

discourse within professional-disabled people relations, such as disabled people as clients, users and customers, and notions of empowerment; changes in the relations between professionals and the state, particularly with the crisis of the welfare state and the introduction of the market into welfare provision; changing legislation in fostering and limiting change; and the growth of the Disabled People's Movement.

The notion of changing professional-disabled people relations we are pursuing here, then, is founded on a shift of control to disabled people. As recognized by Finkelstein and Stuart (1996) there are two components to such a shift. The first is at the personal level of individual disabled people taking an active role in realizing their own goals. As French states:

Disabled people define independence, not in physical terms, but in terms of control. People who are almost totally dependent on others, in a physical sense, can still have independence of thought and action, enabling them to take full and active charge of their lives. (1994d: 49)

The term "empowerment", though inconsistently used, is often invoked to convey the inherent changes in professional-disabled people relations. The second component is collective control of

policy and the organization of services, best achieved, according to Finkelstein and Stuart (1996), through the supervision of the collective services by national and local representative organizations of disabled people. "Consultation" is the most widely applied term.

To a certain extent, the parameters of such a changing relationship are set out in legislation. In some countries, including Australia, the USA, Canada and New Zealand, anti-discrimination legislation can provide a framework for confronting institutionalized discrimination. However, the effectiveness of such legislation is contentious. Certainly the legislation itself needs to be founded on the social model of disability and effective mechanisms for enforcement. Thus, whereas the Americans with Disabilities Act (1990) is viewed as comprehensive civil rights legislation, the more recent Disability Discrimination Act (1995) in Britain is more piecemeal, reflects an individual model of disability and lacks an effective agency of enforcement. In Britain, however, as in other countries, community care policy has been underpinned by legislation which, at least at policy level, sets the context for increased control by disabled over the services they receive, for

instance with the passing of the NHS and Community Care Act (1990) and the Direct Payments Bill (1995).

Despite the potential for a changing relationship, there is little evidence of any shift in power in relationships between professionals and disabled people. There has been recognition that empowerment is essentially a political activity addressing power and control, rather than the development of the capacities of disabled individuals by professional intervention. Williams conveys this:

To recognize clients' experiential knowledge as the foundation for learning, with the professional's expert knowledge at the *service* of the client. . . It removes power from them and hands it over to the client; and locates their base of power with their clients rather than with their professional body. (1993: 12)

Yet reviews of the available evidence consistently suggest that 'health and welfare organizations and the professionals who control them are unwilling or unable to surrender power to their users and thus meaningfully empower them' (Jack, 1995: 38). As Jack suggests, one possible reason for professionals espousal of the notion of empowerment is in response to the introduction of the

market into service provision and the consequent threat to professional autonomy. In this light, professional' claims of empowerment can be seen as protection of their own power by appearing to share it with disabled people (Gomm, 1993: 137).

Moves towards consultation have also been seen as limited rather than reflecting far reaching change. In his overview of the changing scene across Europe, Daunt (1991: 54) suggests that there are signs that service providers are paying more attention to the organizations of disabled people. However, research such as Bewley and Glendinning (1994) show that disabled people face considerable barriers in their involvement in planning community care, particularly those historically marginalized in service provision such as Black and ethnic minority communities and the Deaf community.

Ultimately, it can be argued, the relationship between professionals and disabled people is a reflection of the social structures, ideologies and power relations which disable people with impairments. The impetus for fundamental change is being generated by disabled people, but the focus for change is professional structures, policies, practices and ideologies. Power relations and structures are, by their nature, deeply ingrained and

cosmetic changes mask lack of fundamental change. The challenge for professionals is that, from the experiences of disabled people, they have been part of the disablement of people with impairments. Central to a changing relationship is the changing paradigm from a medical to a social model of disability and, with this, possibilities for professionals to work for and with disabled people in confronting the barriers of institutional discrimination. Jack concluded that 'true empowerment in community care is attainable only through self-help activity and user-led services' (1995: 38). However, many disabled people would agree with Mike du Toit, a South African disabled activist, that:

The movement does not reject the role of the professionals. What we reject is the inappropriateness of so much of the work that is being done, and the inappropriateness of their attitudes, and the complete inappropriateness of their seeking to represent us. (Coleridge, 1993: 77)

As in this chapter, the critique of professional power is pursued as a foundation for relationships in which, as in Brisenden's fantasy, disabled people are in control, rather than forced into dependency.

In this chapter we have considered the relationship between disabled people and health and welfare professionals by tracing the development of professional power and examining the experiences of disabled people, including disabled health and welfare professionals. We have also provided two contrasting case studies of service provision and discussed the rise of the Disabled People's Movement. From this we conclude that the only way forward for health and welfare professionals is to relinquish their power and become disabled people's allies.

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