HELPERS

At first sight, the imagery surrounding helpers in our society seems predominantly positive, focusing on ideas about altruistic sacrifice and beneficent professionalism. For example, doctors are traditionally seen as omnipotent figures, with life-saving powers. The white coat signifies the hygienic, omniscient nature of science, but with overtones of religious power and purification. The stethoscope symbolises the practioner's ability to uncover the truth of the body, and to gain knowledge unavailable to the patient. In television dramas, doctors tend to be successful, authoritative and good, for example Bill Cosby's character of Dr Huxtable. Nurses, while overlaid with a sexist element of erotic frisson, have an image as angelic helpers, underpaid but devoted to their calling. Again, in the film *Truly, Madly, Deeply,* the heroine, played by Juliet Stevenson, is made a teacher of people with learning difficulties, in order to symbolise her all-round niceness. Workers in the caring professions, with the general exception of social workers, are usually highly valued and respected. Volunteers are seen as pillars of the community, rewarded with medals and admiration. Patients and service users remain silenced, objectified and othered, in a discourse where they exist only to have things done to them or for them.

Looking more closely at images of the doctor in literary works, it is possible to develop a more complex picture, showing the competing representations of the professional helper. The dominant model remains that of the beneficent and altruistic healer. For example, in *Bleak House,* Allan Woodcourt is seldom centre-stage, but is nevertheless held up as an ideal of the medical professional. In his work in the colonies and at home he is self-sacrificing, skilled and motivated by an essential goodness. Esther Summerson - admittedly biased, being his wife - summarises this image of the devoted doctor:

'I never walk out with my husband, but I hear the people bless him. I never go into a house of any degree, but I hear his praises, or see them in grateful eyes. I never lie down at night, but I know that in the course of that day he has alleviated pain and soothed some fellow-creature in the time of need. I know that from the beds of those who were past recovery, thanks have often, often gone up in the last hour; for his patient ministration. ' (Dickens, 1994, 807)

Alternatively, there is the figure of Dr Bovary, in Flaubert's novel *Madame Bovary* (1981). The whole of this novel is a symbolic exploration of normality and deviance, as Flaubert uses the dissatisfaction of Emma Bovary with mundane provincial life to express his own hatred for bourgeois existence. One particular episode explores the role of the professional and the disabled body, when Emma's

husband, Charles Bovary, is incited by her and by the chemist Homais to attempt a pioneering operation on the stable-boy, Hippolyte. Hippolyte has a club foot, but is clearly very well adapted to his physical difference. Yet his appearance seems bestial – his foot is 'equine' – and his name reinforces the connection to horses. According to 'progressive' opinion, he must be corrected, brought to conform to the norm. Charles performs this operation which goes badly wrong, and in the end an older, more traditional doctor has to be summoned to remedy the situation. Dr Bovary highlights the image of the doctor as arrogant, as more concerned with their own fame and success than the well-being of the patient. The doctor knows what is best for the patient, whose role is to provide an opportunity for the demonstration of their power. Moreover the example suggests that doctoring may have dangerous side-effects and unintended outcomes, a process which Ivan Illich has called iatrogenesis. Finally, the episode predicts a world in which medical interventions are normalizing, being more concerned with eliminating difference than improving quality of life.

A third literary example highlights the underlying theme of many representations: in Stevenson's *Treasure Island*, Dr. Livesey is seen as a gentleman, a person of social power. As a medical practitioner, he is prepared to assist the buccaneers in the enemy camp, but otherwise he is firmly of the Squire's party. Whereas Dr Woodcourt achieves a nobility though his goodness, and Dr Bovary aspires to status through innovative interventions, Dr Livesey reinforces the idea that doctors are commanding figures in society, coming from the upper classes and demanding respect and obedience. That is to say, alongside the image of the doctor as the helper is an equally powerful image of the doctor as someone – usually a man – of authority. The positive image of helpers, therefore, needs to be supplemented by a skepticism as to the role of professionalism. Important questions are raised about the nature of power, the normalising effects of therapy, and the differences in status between helpers and those they aim to serve.

In reality of course, doctors and other professionals are no more consistently altruistic and benign than other human beings. Their ranks include murderers like Dr Crippen, and agents of genocide such as the Nazi doctors or Dr Radovan Karadjic. Alternatively, doctors can be corrupt, inefficient or incompetent, rather than evil, as the Bristol cardiac scandal or the example of consultant gynaecologist Rodney Ledward demonstrates. Yet images of medical and other professionals still tend to be saintly, and systems of accountability and control continue to be inadequate. We should not be surprised by the occasional bad apple, but we should be concerned that so many of them get away with their errors or crimes for so long. The argument of this chapter is that professionalism causes more problems than it solves, and that the power and status of helpers undermine their capacity to help.

One of the major findings of Mildred Blaxter's research into the meaning of disability was the vast complexity of organisations and services which were available to disabled people: her book contains a table of the different sources and types of help which resembles an intricate electronic circuit diagram (Blaxter,

1980, 19). Mike Oliver (1987) quotes a list of the 'helpers' working in the field of disability which includes 23 different categories of professionals, some of them further subdivided. Despite reforms in the NHS and social services, this nightmare of specialisation remains a problem for all those requiring help, whether on the basis of age, disability or other issues. Together with the daunting complexity of welfare benefits, this situation shows exactly how help can be provided in confusing and disempowering ways.

But the scepticism expressed by service users does not concern only the professional maze, but also the role of professionals and the power of professionals. For example, Ken Davis complains about the way that this army of disability professionals refer to people like him as a 'client'. For him, the term 'client' implies a measure of choice - just as when one goes to a solicitor or accountant. Yet disabled people do not have the power to take their custom elsewhere if they are dissatisfied with a disability professional: *To all intents and purposes, these denizens of the disability industry are the gatekeepers to the services we need. We either go through them or do without. Take it or leave it.'* (Davis, 1993, 197). Davis is sceptical about the role of these professionals, the way they build their careers on the backs of disabled people, and the control they exert over the disabled population, dominating the terminology and philosophy and practices of the' disability industry'.

Mike Oliver has developed this concept of the disability industry, in order to argue that the real purpose of the welfare state is to benefit those involved in the production of services rather than those involved in their consumption, By far the biggest part of the budget goes on salaries: *'Hence able-bodied professionals consume the employment services of the welfare state to a far greater extent than disabled people consume the health or social services of the very same welfare state,'* (Oliver, 1991 157), An example he provides is the 1970 Chronically Sick and Disable Persons Act, which spawned more professionals in social work, occupational therapy and so forth, and became known as 'the professionals' charter' He refers also to the]98] Education Act, which raised hopes that disabled children would be integrated into mainstream schools, but, Oliver concludes *'In fact it resulted in local authorities employing more educational psychologists and administrators in order to keep disabled children in precisely the same places that they were in before the Act was passed.'* (1991, 157)

Millions of people are employed in the health and welfare industries: the National Health Service is the largest employer in the UK. Vic Finkelstein explores the irony that those he calls 'people with abilities' are dependent on disabled people for their salaries and their career development: there is a never-ending demand for more and more health and we are professionals to *care* for disabled people while the latter remain unemployed or regarded as unemployable.

There is often a significant different in socio-economic status between professionals and those they help, a well as gender and racial differences.

Moreover, very few professionals have impairments. For example, the vast majority of doctors are fit and healthy people from higher social classes, who may not be able to understand or relate to the experience of many of their patients. The disabled academic Irving Zola had no illusions about the structural position of doctors in America: ' *society is left with the uncomfortable phenomena of a portion of its population, living and living well, off the sufferings of others and to some extent even unwittingly having a vested interest in the continuing existence of such problems.'* (1977, 66).

These questions about the parasitic nature of those who are well-paid to provide for those who need help are paralleled by the evidence of the power and status of professionals. Titmuss wrote that professionals are preeminently people with status problems (1968, 72), while for Freidson (1970), the label 'professional' referred to the way in which a group of workers have managed to exert occupational control. Analysts such as Freidson, Zola and Illich have challenged the ideology that professionalism exists to serve patients and service users, and demonstrated the ways in which professionalism can be seen, in reality, to exist to benefit professionals themselves. Making the power of professionals explicit challenges the concept of caring which is the heart of professionalism, creating a dissonance which it is hard to ignore.

In the last decades of the twentieth century, new paradigms of welfare have to a certain extent displaced the power of professionals. Introducing private sector methods Into public sector services, in the form of internal markets and manage-rialism, has undermined the autonomy of professionals - to a large extent in the case of social workers (Harris, 998), and to a lesser extent in the case of doctors. However, the experience of service users has not been explicitly considered in these changes, even though Conservative governments promoted reform on the basis of consumer choice and power. My contention is that while the working conditions of professionals may have changed, the experience of users has not improved, and that. the 'public servants' retain their colonial power. This chapter focuses on doctors, as the ideal-type professional, with shorter discussions of other professionals who aspire to follow the same trajectory of status and control. Finally, there will be a consideration of those helpers who do not enjoy professional status, but may still exert power over those they 'look after'.

Power of definition

A key element in the power f professionals lies in the ability to define the nature of the problem with which they are concerned. This starts with the identification of a need, which justifies the presence and power of the helper:

'Need, used as a noun, became the fodder on which professionals were fattened into dominance. ' (Illich, 1977 a, 22)

The need has to be translated into a deficiency, meaning something which has to be corrected or compensated for. This deficiency is individualised: the person is taken out of the context which may be the cause of their problem, and structural solutions are ignored for personal ones. For example, corrective surgery -such as cosmetic surgery for people with Downs, or limb-lengthening for people with achondropasia - is provided instead of working to change the cultural prejudice which makes life difficult for people who look different.

But this definitional power concerns not just the problem itself, but also the person with the problem. The client is constructed by inference through professional definition of need: the disabled person, or the person with mental illness, could be seen as a product of the medical professionals or welfare agencies with which they come into contact. If the individual is the problem, then the professional is the solution. And, because it is in the nature of professions to be self-regulating, it is the professionals themselves who decide whether the help they provide is effective. A combination of medical imperialism, and the tendency of modern societies to give doctors the onus for difficult decisions, ever extends the domain of medicalisation. In Illich's vision of medical nemesis, biomedicine extend its jurisdiction over more and more areas, prescribing drugs to healthy people, undermining the ability of society to look after itself and to experience the natural processes of embodiment, frailty, suffering and death.

Connected with the power of definition is the power of surveillance and identification. Social workers and health visitors enter the home in order to provide advice and counselling, and to inspect childcare standards. Parents are regarded as in need of professional support, as incompetent and deskilled. For Nick Fox, the new professionalisation of care constitutes a technology of surveillance: *These discourses of care professions create the disciplinary vigil of care, which is more to do with power and control than with values of love, trust and giving.'* (1995, 108). In this analysis, professions are playing a moral role, filling the gap vacated by priests in secular society: *'Professionals tell you what you need, and claim the power to proscribe. They not only recommend what is good, but actually ordain what is right.'* (Illich, 1977a, 17).

By monopolising expertise and extending their power of control, Illich argues that *'the professional has mutated into a crusading and commandeering philanthropist'* (Illich, 1977a, 19). When an elite group of practitioners claim to know best what is right for the public, when there are few democratic controls, it is unsurprising that critics come to believe that professionals are a conspiracy against the people. Lawyers may be the professionals that the public love to hate, but perhaps doctors are the professionals that the public hate to need.

Role of knowledge

The power of definition and surveillance is inextricably entwined with the successful claim to knowledge which lies at the heart of professionalism. By

establishing an area of expertise, and excluding others from it, superior status is ensured: the historic process hereby predominantly male obstetricians achieved dominance over female midwives, partly due to monopoly of new techniques such as the forceps, is a classic example of this. Fox's Foucauldian analysis links this superior claim to knowledge with increasing authority over the patient:

'The association of power with knowledge suggests that in the context of care, the professionalisation of caring (creating a discipline) cannot but lead to a disciplining of one' s clients.' (Fox, 1995, 111)

Professional codification leads to a body of knowledge which creates a discipline which generates authority and power and enables the professionals to construct the now docile bodies of care recipients. Moreover, as care becomes grounded in scientific knowledge and professional expertise, the patient themselves disappears from the frame. Jewson has written how a reliance on the testimony of the sick person was replaced with an increasing focus on signs and symptoms, the extension of the medical gaze into the body, and the development of diagnostic and now genetic tests. Fox suggests that the result is an edifice of theory and professional discourse which no longer refers explicitly to nursing patients (1995, 114). In our research with disabled children, we often encountered psychologists and other educational professionals who saw the children as diagnostic labels, rather than as people.

The historical trajectory of the medical profession has established a precedent which is now being emulated by lower status professions such as nurses, occupational therapists, and social workers. There is a upward spiral of occupational development by which these related disciplines attempt to monopolise areas of expertise, exclude unqualified practioners from using their job title, and increase their own independence, scope of competence, and hence authority and income. As an example, social work and nursing are both now offered as degree courses, stressing the need for a body of academic knowledge, rather than the vocational training and personal experience which were the former qualifications. This increasing professionalisation of different forms of healing mean that they become ways of exercising power instead of offering service.

According to the Brazilian educationalist Paolo Freire, possession of a body of expertise leads to a proselytizing tendency among professionals:

'Whatever the speciality that brings them into contact with the people, they are almost unshakeably convinced that it is their mission to 'give' the latter their knowledge and techniques. They see themselves as 'promoters' of the people. (1972, 124).

Perhaps this observation takes us back to Dr Bovary, and his orthopaedic experiments. It might also relate to those advocates of eugenics and sexual hygiene in the early twentieth century who campaigned against the unrestrained sexuality

of the lower classes, or implemented sterilisation and euthenasia against the hereditarily unfit.

In the modem world, there is therefore an ambivalence in our relationship with doctors. Strident criticisms coexist with deep dependency. For example, within the AIDS field, there is a contradictory relationship with science, in which medics are both allies and enemies. People with the virus do not want their lives to be medicalised, but also do not want to miss out on possible treatments:

'Community activists often seem to adopt positions where they are very critical of the claims of bio-medical knowledge while seeking out every "advance" of medical research with an almost religious faith in its findings.' (Altman, 1994 121)

Equally, many disabled people survive only because of the effectiveness of modern medicine. Spinal-injured soldiers during the First World War would generally have died very rapidly; during the Second World War, the life expectancy of a spinally injured soldier was about two years; since Vietnam, spinal chord injury no longer implies a significantly shortened lifespan. Another example is the way in which premature babies or people with spina bifida or other congenital impairment are enabled to survive these traumas and grow to adulthood only because of the effectiveness of hospital medicine. Finally, modern pharmaceuticals have ensured that cognitive impairments such as epilepsy and schizophrenia can be managed fairly successfully. Yet disabled people and mental health survivors, alongside people with HIV/AIDS, continue to be strongly critical of the power and role of the medical profession, and with good cause.

There is a paradox here. When we are ill, we want our doctors to be omnipotent. We wish to be able to surrender responsibility and trust them to make us better. It is in our interest to maintain the illusion of the beneficent and all- powerful medical professional, because the alternative is to accept the frightening unpredictability and uncontrollability of human embodiment. We can't live with them, and we can't live without them. Yet, of course, medicine cannot deliver all that it promises, or fulfil all of our hopes. Often doctors promote the idea of their own omniscience, because it suits them and their patients like it. But the reality is that biomedicine cannot solve all the problems, and even causes as many as it solves, for example, through the side-effects of the powerful protease inhibitors taken by people with AIDS, or the increasing problem of drug-resistant bacteria and viruses.

One person with HIV/AIDS whom I interviewed commented about his physicians, *'they don't really have all the answers, do they? They just look at you.'* His monthly visits to the clinic involve an examination of his lungs, eyes and skin, and tests for viral load, liver functions and so forth: his consultations centred on a computer printout. The doctor reassures him that everything is okay, that the clinical signs are all normal. But, as he said to me: *'well its not - I've got headaches and I've got aching joints.'* In response to this subjective account, the doctor replies to him:

'Don't tell us what's wrong with you. We just want to know about the good things.' The negative comments are not recorded, only the positive data.

In the disability arts world, there is a joke circulating about doctors which makes a useful comparison. A disabled person dies and goes to Heaven. When St Peter meets him at the Pearly Gates, he will only enter once he has been assured that there are no doctors in Heaven. Having been ordered around by doctors all his life, he doesn't want to spend eternity dodging members of the medical profession. To his alarm, a few days later he sees a man in a white coat, with a long white beard and stethoscope round his neck, pushing his way through the crowds of the Blessed. The man in the white coat keeps on repeating *'Get out of my way, I'm a doctor!'.* In horror, the disabled person returns to St Peter and complains about what he has witnessed. St Peter tells him not to be alarmed. *'That's only God. He just thinks he's a doctor:'* Believing in doctors is a bit like believing in God. It is about taking refuge in the hands of one more capable than oneself who can take responsibility and look after you when things go wrong. Yet doctors are not all-powerful. They cannot live up to the expectation we have of them, because even at best they are fallible, and their remedies have limited efficacy. Perhaps a more balanced appraisal of the success of biomedicine would contribute to a more egalitarian relationship with doctors. Certainly, the present equation of knowledge and power contributes to the alienation of the patient.

Failure of communication

Knowledge also plays a major role in the common complaint that professionals are incapable of communicating properly with patients and service users:

'How many leave hospital healed of their physical illness but hurt in their feelings by the impersonal treatment they received; how many return from their consultations with psychiatrists, psychologists, social workers or counsellors, increasingly irritated by the non-committal attitude and professional distance they encounter?' (Nouwen, 1976,86)

The origins of this problem may lie in three factors: the inevitable gap between lay and expert knowledge; the way in which doctors are trained and socialised; and the levels of stress involved in practising medicine. The same factors may apply, in different forms, for other professional helpers.

The discursive gap between medical experts and the general public remains, despite the popularity of hospital soap operas. One outcome of the development of medical knowledge may be an increasing distance from lay understanding. This may be result of the use of incomprehensible jargon or specialist vocabulary: *'The language of modernized professional services mystifies both problem and solution so that citizen evaluation becomes impossible. '*(McKnight, 1977, 86). Because professionals operate in a separate world from the public, and because of the distance that exists between the helper and the helped, serious communication

failures can result. As Hugman argues, *'thinking, doing, and speaking the profession cannot be separated'* (Hugman, 1991, 127).

Moreover, the high knowledge requirements of contemporary biomedicine structure the form of the procession. Medical students are selected on the basis of academic success, not skill in communicating or in helping others. Most are white and upper-middle-class, and come from medical families. Many choose medicine because of its material rewards rather than for altruistic reasons. Recruits then go through an intense period of education, which forms a socialisation process which ensures that the new cohort of doctors shares the values of previous generations. Clinical and technical knowledge is prioritised over the learning of communication skills or psychological insight or social understanding, despite recent reforms. Doctors I interviewed felt that their training had been about limiting the imagination, reducing receptiveness and sensitivity, and channelling reading and thinking into narrow paths. For the two to three years of clinical training, the immense pressure of learning and long hours on duty, plus a tendency to socialise almost exclusively with other medics, meant that their cohort of trainees became somewhat removed from the outside world, and abandoned many outside connections and interests. The result was sometimes an 'us and them' mentality, and often a failure to empathise with or understand patients.

Specialisation and experience does not necessarily increase the skills of doctors at dealing with patients. For example, research found that medical students at the beginning of their training were better at engaging with people with profound learning difficulties than those at the end of training (Fraser, 1992, 27). When the public have contact with people with learning difficulties, their attitudes improve, yet research found that trained psychologists had more negative opinions of people with learning difficulties even than unacquainted members of the general public (St Claire, 1986). Again, one doctor I interviewed mentioned a ward round where her consultant, on meeting an older female patient, asked 'How are your thrombi?'. Unsurprisingly, the patient was mystified, at which point the doctor asked, in patronising tones, 'How are your thrombo-embolic phenomena?' It was only after a nurse explained 'He means clots in your legs' that the woman was able to understand and provide the information requested. Clearly the consultant had forgotten that the patient did not have access to professional knowledge, let alone hospital slang.

In fact, the traditional ward round was the key site of failed doctor/patient interaction. Often, consultants still sweep onto wards and into clinics like minor potentates, peremptory, sometimes benign, eternally all-powerful, and arrive at the bedside with an entourage of junior doctors, medical students and nurses. Patients exist to display symptoms, rather than as individuals. Another specialist registrar told me an anecdote about a consultant who said to her: 'I find the ward round goes a lot quicker if you don't talk to the patients.' The ward round has historically existed for the convenience of senior doctors, not the comfort and consolation of patients. It may be an effective means for gathering information, but

it is not a private or sensitive context in which to convey serious news. My colleague Pam Carter reflected on the moment she learned of her terminal diagnosis:

'I might have been expected to feel ambivalence about doctors. They are the messengers. The knowledge (or often absence of it), power and superior position in every kind of hierarchy mean that the possibilities of equality and conversation are slender. ..I have now added to my experience that scene we all know when the consultant delivers his verdict (in my case truly dreadful and no holds barred) not only to me, my partner; his entourage (a large number of whom I had never seen before, as I had not, in fact, seen him), but also I presume to every patient within earshot. '

Equally distressing anecdotes about the communication of information have been provided by parents of newborn babies with impairments or other complications. SCOPE's Right from the Start campaign challenges the way that professionals break the news of impairment to parents: up to 80 per cent of parents in their survey were dissatisfied with the way professionals had broken the news of their child's disability and with the help given afterwards. The Downs Syndrome Association (Rutter and Seyman, 1999) have collected many examples of the crass and insensitive behaviour of doctors. One mother wrote: *'[The paediatrician] then came back with her, plonked her on my tummy and said, "You have a Mongol".'.* Other parents had been told it would have been better if their baby had died at birth, or asked why they hadn't used amniocentesis. Another mother said: *'We were very badly treated when he was born. We were told he was a rag doll and would be good for nothing.'* No wonder one parent concluded: *'The treatment, understanding and care we received when our son was born was disgusting. I will never forget or forgive the nightmare we had in hospital. '*

The use of the word 'Mongol' in the earlier quotation demonstrates how language can reveal prejudice, as well as creating distance through jargon. Another example is the now declining tendency of doctors to write coded 'diagnoses' on the medical notes of patients, including acronyms such as NON (normal for Newcastle), GOK (God only knows) and SIG (stroppy ignorant git).

Other ways in which communication barriers operate include the tendency to use infantilising terminology -for example in the antenatal encounter –or for professionals to hide behind titles, relying on the anonymity of their role. Sometimes, for instance, a doctor or social worker will be referred to by their surname, while the client is known by their first name.

Many people experience doctors, especially consultants, as arrogant and uncaring. There are perhaps several reasons for this. As observed earlier, doctors tend to be drawn from a narrow stratum at the top of society, and consequently to enjoy the associated confidence, cultural capital and. privileges. Second, Celia Davies argues that the profession is a classic expression of masculinity (1998, 133). The

dominant values are impartiality and impersonality: control of emotion, detachment, autonomy. Senior doctors depend on the adjunct work of others to prepare and clean up after them, usually female nurses, technicians and orderlies. They are used to being obeyed, facilitated, supported, respected, all of which contributes to egotism. Moreover the male culture means that women, to get ahead, have to emulate the men and suppress elements of empathy or softness which might be associated with femininity.

Moreover, unlike the traditional image of God, or of the loving parent, with the best will in the world, doctors do not see our ailments in the way we do. For us, our problem is the centre of our life. Whether it is a nagging pain, or a chronic illness, or a worry about the implications of a lump or a sensation, it is of literally life-and-death importance to us. The doctor's diagnosis, and the doctor's treatment, cannot be more vital. Yet, for the doctor, we are just one of a number of patients they are seeing that day, one of hundreds of thousands they will see over their career. 0ur cancer or our back pain is just another example of a condition with which they are tediously familiar, and they cannot be expected to see it in the way we do.

Therefore perhaps it is wrong to see the doctor as cruel or uncaring. It is just that he or she cannot be expected to empathise, both because they do not know what it is like and because they know just what it is like. This is why medical information may sometime be communicated with a lack of sensitivity. For the professional it may be routine and insignificant. For the individual it is devastating, unrepeatable and profound. The whole universe is contained in that moment, whereas for a doctor it is a difficult or sad or tiresome task during a long and stressful day or week. Again, many doctors may not be emotionally or psychologically equipped for the stress of communicating terrible diagnoses, which may lead to what seems like abruptness.

Finally, the nature of medical practice perhaps demands a certain level of arrogance and detachment. The responsibility of performing a major operation, or presiding over a birth, could be difficult to take on unless one is supremely confident in one's own abilities. Cutting off from any idea that the body before you is a real person, whose life is literally in your hands, may be necessary before making an incision into their flesh. Equally, if one is to endure the suffering and death of other on a daily basis, perhaps a psychic defence is to distance oneself, not just from people on an individual basis, but also from patients as a class of person. Recognising one's own frailty and mortality in every person one treats may be an impossible barrier to continuing practice. Of course, there are many kinds of doctor. The personalities, and reputations, of surgeons and gynaecologists are different from those of general practitioners and psychiatrists, both because different people enter those specialisms, and also because there are distinct strains and pressures, and different relationships with patients. Yet medicine remains perhaps the profession with the most weighty responsibilities, and the National Health Service one of the most stressful sectors in which to work.

Low status helpers

Many of the issues which are exemplified in the case of doctors are also evidenced in the practice Of social workers and others working in the social welfare field. However, the levels of autonomy and power decrease further down the occupational ladder, particularly as the tasks carried out by social workers and care assistants, for example, are not technically complex or highly specialised. Nurses, social workers and care assistants work within bureaucratic structures which place limits on their role and the way in which help can be delivered. Like doctors, these lower-status helpers work within a tradition which explains social problems such as disability in individualistic terms.

Both social workers and nurses have their origins in nineteenth-century philanthropy. In their origins, these occupations are associated with the idea of vocation and service to others - taking the form of the devotion and selflessness which was of course particularly associated with women. Nurses were taught to be silent in the face of rudeness, insults and general lack of respect from some doctors. Lack of power, poor pay and conditions, and the competing demands of professionals on the one hand, and patients and users on the other, mean that the role of social worker, nurse and care assistant can be experienced as thankless and stressful. Such workers face all the difficulties of working as a helper, without the status and other privileges enjoyed by doctors and other higher professionals. Bombarded with work, the result can be a failure to deliver effective helping:

'Their senses become dulled and their sensibilities blunted; they suffer from emotional saturation or drought. Their helping can become automatic, unspontaneous and quite joyless they come to resent their clients. ' (Jordan, 1979, 29). Jordan suggests. that occupational hazards of these roles include insecurity, pressure, defensiveness, anxiety and lack of confidence.

Care assistants, perhaps entirely lacking in training or qualifications, are among the lowest-paid and most exploited members of the workforce. As Colin Barnes (1990) observed in his study of day centres, they may have much in common with the disabled people whom they are paid to support. The consequence of the exploitation of the workforce may be depersonalisation of the clients, as in old people's homes:

'Depersonalizing the people being cared for; disaggregating them into a series of tasks is a way whereby staff can protect themselves from confronting the pain of people -processing organizations where both carers and cared-for alike are devalued by and unsupported in their social context. ' (Fennell et al., 1988, 144)

Kathryn Ellis (1993) attributes some of the low morale expressed by social workers to their new role as gatekeepers within community care, working within a financially constrained environment: they have a problem of dual accountability, to the agency for which they work, and to the user whom they are professionally

bound to support and help. She proposes a more explicit set of rationing criteria, so that decisions can be understood or challenged.

Disabled people and other service users express many criticisms of the resulting attitude and performance of low-status helpers. Some comments relate to the bureaucratic context in which helpers work, the maze of regulations and the lack of flexibility. For example, district nurses are restricted to nursing tasks, delivering a service which fails to assist disabled people to exert control over their lives. Whereas home helps started out as cleaners, since the advent of community care they have replaced social workers as cheaper, lower-status, care workers. Home helps also take over from nurses, taking on roles such as changing dressings Although home helps may be cheaper, they lack proper training. And the result is that homecare no longer provides the housework and shopping which was traditionally the task of the home help.

Other complaints relate to the way services are delivered. For example, people do not like the way their homes are invaded by strangers and the resulting lack of privacy. There may be a lack of continuity of care because a different helper arrives each week. Helper may be late or unreliable. For example, service users report that uncertainty over what time the nurse will arrive to help with a bath can disrupt half a day and cause stress. Helpers may ignore the disabled or elderly person and talk to able-bodied relative or carer instead, or may be patronising or bossy. Gay disabled people have sometimes complained about the homophobia of home helps or care assistants. Helpers cause problems when they move things around the house, causing unseen hazards for blind people, or making it difficult to find things. Their help may be experienced as meddling and interference, rather than responsive assistance.

There is a considerable level of antagonism and cynicism towards the social work profession from disabled people and their organisations, as my 1996 research with disabled people revealed. One activist said to me: *'I am appalled at the standard of qualified social workers.'* Respondents *'struggled to see a role for social workers in disability',* because it was felt that social workers had nothing useful to offer disabled people, not being skilled in equipment, design, planning or welfare rights: *in disability, social work is a redundant profession'.* There was scepticism regarding the skills and appropriateness of social workers fulfilling a counselling role. Neither was multi-agency working or the multidisciplinary culture felt to be a reality: *'the culture isn't there for them to be effective coordinators or assessors'.*
Social workers are now mainly involved in care management, rather than direct help, yet they are still often resented by disabled people. Many service users feel unhappy because of lack of knowledge of their entitlements. In a context of financial constraint, it is cheaper not to give full information of what might be available: in this way, ignorance is a form of rationing because, as one person said, *'What you don't know, you don't get.'* Regulations provide further barriers: for example, one man I interviewed had been told that he would not qualify for an

electric wheelchair if he was able to walk around inside the house. Yet, for him, the point of the wheelchair was to get out and travel around the neighbourhood, which he could not manage. Again, although he had received a manual wheelchair, no one was able to help when it needed to be mended. Such experiences seem to provide more evidence for the suggestion that the current situation is one of minimal services, maximum dependency.

However, there are signs of different models developing, bypassing the situation of statutory social workers trapped between the pressures of community care procedures and the frustration and antagonism of disempowered disabled clients. Often this is in voluntary organisations, and particularly through self-organised voluntary groups such as the Spinal Injuries Association (d' Aboville., 1991). In these examples, social workers are not operating as gatekeepers to state benefits and services, and workers and clients are able to interact in a situation of respect and mutual equality, without the barriers of professional expertise or statutory restriction.

Training for social workers, home helps and care assistants is vitally important. Disability equality issues, for example, need to be central to the course, rather than the traditional medical and psychosocial models of intervention. Collective and structural issues, rather than an individual approach, must be prioritised. Yet my research into social work education suggests that the dominant philosophy of social work education, often based on trying to understand *'what it's like'* for 'clients, does not sit well with the principles of disability equality. The medical model assumption that impairment is inevitably bad predominates in thinking. Anti-discriminatory practice is often an adjunct to professional and practice issues rather than a substantive core of it. However, evidence shows that it is possible to develop social-model approaches to social work and disability (Morris, 1994a, 23ff.) This also means drawing on new ways of working, stressing partnership and mutuality, and adapting training to the changing roles of social workers.

Changing professions

In the 1980s and 1990s, new health and welfare approaches have challenged the dominance of professionals such as doctors and social workers, while not necessarily increasing accountability to service users, or improving the face-to-face relationship. The Conservative government introduction of market principles into medical and social services were ostensibly designed to increase efficiency and consumer choice, although the changes seem in retrospect to have been about the commodification and rationing of the welfare state.

One key dimension of the change was the increase in managerialism. For example, social workers' roles have changed from direct casework towards the assessment and management of care packages. In general there has been an attempt to circumscribe the power of professionals through managerialism and restructuring. This is partly a response to various social services scandals and attacks on social

work by the media and the right. Private sector emphases on flexibility, innovation, quality control and auditing now dominate public services. It is an open question as to whether it is better to be on the receiving end of the new rationalised management structures or the traditional relationship-based social work practice with all the difficulties which disabled radicals have identified. Neither is adequate or ideal.

In particular, the new processes of needs assessment cannot accommodate individuated recognition and mutual response:

'Any sense of the richness and incommensurability of human need has been lost because its grounding in specific human histories and relationships cannot be interrogated in standardised assessment formats, and the meeting of such needs poses awesome problems of auditing.' (Froggett, 1996, 119)

Not all service users will need the psychosocial aspect of help, but the new system may leave those service users who do missing out on a vital element of the social work role unless these needs can be met in a different way. Perhaps there it is important to ensure that social work practice involves a relationship with users, as well as the procedural rights-based approach. David Howe develops a powerful argument for the return of psychodynamically informed practice, to improve client's security, self-esteem, self-efficacy and sense of autonomy, rather than attempting *'to deal with human distress and difficulty by use of impersonal statutes and rote-responses'* (Howe, 1998, 54).

Another element of the new service discourse was a stress on consumerism. While left critics of welfare services had campaigned for welfare rights and against paternalism, the new stress on service users as customers was based on the model of the market, the extension of choice, and an attack on 'the collectivist state' (Crinson, 1998, 1230). For example, John Major's government introduced the Patient's Charter, which gave token 'rights' to health service users. Again, publishing league tables of hospitals provides the illusion of patient choice, in a context of continuing cash constraints on the National Health Service and increasingly interventionist management from central government. There has been limited empowerment for service users, despite the talk of partnership. While New Labour have reduced the role of the market, they remain committed to the concept of the Patient's Charter, and to the consumerist rhetoric of choice, rather than the radical concept of democratic accountability and community participation.

Finally, as a reaction to notorious bad cases, the late 1990s have seen another attempt to place medical practice under lay scrutiny. The advent of clinical governance suggests that the traditional autonomy of the doctor will be eroded further. Tory reforms exerted organisational and budgetary control over practitioners, and were consequently resisted by professional groupings. The Commission for Health Improvement, and moves towards revalidation, should ensure that doctors are held to account for their skills, and are an advance over the

self-policing of the General Medical Council. Now social and communication skills should be stressed alongside technical competence, and training should highlight the art of medicine alongside the science. It remains to be seen whether these innovations will genuinely improve services to patients, or merely add stress and anxiety to doctors' lives without weeding out the minority of incompetent practitioners.

No-status helpers

At the bottom of the helping hierarchy come the unpaid, non-status carers and volunteers who provide services out of love and duty. Many commentators have demonstrated how the current framework of community care places the responsibility for supporting disabled and elderly people predominantly on unpaid carers. The welfare state is saved the cost of professional help in the home, and also the cost of residential care for those who could not cope independently in the community. There has been considerable concern over the impact on those who provide this help: feminists particularly have challenged the tendency for women to be the major carers. As Gillian Dalley suggests, *'Women have internalised the altruistic ideal; society has capitalised on it'* (1988, 18). More recently, the situation of children caring for disabled parents has also been identified and challenged. People who need help are devalued, and so is the process of providing ordinary and everyday forms of help: *'Caring is often constituted socially in a way that makes caring work into the work of the least well off members of society'* (Tronto, 1993, 112).

In this discussion, however, I will be taking the part of those disabled feminists who have challenged the construction of the caring debate, in order to explore the ways in which those who receive care are disempowered and marginalised. This is not to deny the major and negative impacts on unpaid carers: as Brandon writes about caring in general, *'Helping is not socialized masochism and the helper has also a right to satisfaction, joy and love from the process'* (1990, 27). Instead, it is to express scepticism about the caring industry and concern that the very real problems of those who provide care may distract from and take priority over the rights of those who receive it. For many disabled or older people, relying totally on one person when they are a partner or a parent leads to powerlessness and isolation. In the worst cases people may suffer neglect or abuse.

Both the contemporary profile and the whole concept of the carer originated as recently as the 1980s. For example, the Carers National Association was formed in 1986. A key 'moral entrepreneur' in the social construction of the category was Jill Pitkeathley, whose book defined a carer as

'someone whose life is in some way restricted by the need to be responsible for the care of someone who is mentally ill, mentally handicapped, physically disabled or whose health is impaired by sickness or old age. ' (1989, 11)

This statement shows how the notion of the carer rests on the construction of the category of helpless person who requires care. The terminology used by Pitkeathley includes words such as 'dependent person', 'sufferers', 'heavily dependent person'. Two key distinctions are suggested: first, 'caring' is reserved for unpaid rather than paid care ; second, 'normal' caring (for example, caring for children) is differentiated from this other kind of caring, which is not time-limited or reciprocal. Yet while children eventually grow up, elderly relatives eventually die. And surely you care for your elderly relatives because they cared for you, and your own children may do the same for you in future.

In stressing the problems of carers, Pitkeathley makes totalising generalisations that stress the negative rather than the positive aspects of the relationship, and that reinforce the idea of the helped person as burden. For example, she suggests that carers experience isolation, being undervalued, fear, resentment, anger, guilt, embarrassment, role reversal, sense of loss, effects of emotional stress, strain on relationships and bereavement. Undoubtedly many do, but the effect is to blame the victim, and to ignore the structural causes of the difficulties facing carers.

The solutions proposed by Pitkeathley echo those feminists who proposed institutionalisation and residential care: for example, she talks about the need to move away from a nuclear family model towards a collectivist approach. Yet she does not consider the views and preferences of disabled and older people themselves. Again, she opposes the idea that direct payments to disabled people would solve the problem of unpaid and exploitative care: because of her overwhelming focus on the, needs of the carer, she suggests that the money should go direct to them, not to the service users. Much of the philosophy, if not the financial suggestions, contained in Pitkeathley's book went into the 1995 Carers Act, which defined a carer as someone providing more than 20 hours of care per week.

For the disability movement the key to solving the problem of care is to empower disabled people themselves. For example, direct payments would allow disabled people to employ personal assistants rather than rely on unpaid care. Equally, given the contentious academic debates about the role of children as carers, proper personal assistance schemes would avoid this necessity. When I interviewed disabled people about community care in 1996, many voiced suspicion that meeting the needs of carers is seen by government as a cheaper option in the short term. Carers have the 'moral high ground', and are seen as safe. It was suggested that statutory services found it easier to consult and talk with carers than with disabled people, and this could be a way in which consultation bypasses disabled users: the phrase 'users and carers' was a way of avoiding disabled people. One disabled respondent spoke about his local carers' organisation, which did not even have a fully building: *'I wish I had kinder things to say about carers' organisations. I don't.'* He went on to add , *'to my mind, the more you increase the rights of carers, the more you take them away from disabled people'.*

Disabled commentators recognise the difficulties facing carers, but stress equally the origins of the problem in the oppression of disabled people. Morris argues, *'Relying on a family member creates significant restraints on the autonomy of both the disabled person and the person providing the help'* (1993, 153). The stress on commonality highlights, for example, that residential care itself involves the exploitation of poorly paid and often female staff; that many carers are men; that the majority of the people receiving care are themselves women; and that many care users are also care providers, for example as parents themselves or as children of ageing parents. This evidence goes some way to dissolving the polarity between carers and cared-for.   Drawing on Morris's work, Bill Bytheway and Julia Johnson (1998) have analysed the social construction of 'carers', and challenged the perspective of the carers' movement. The highlight the concept of 'caring systems' in which mutuality plays a key role, and conclude that care should be reconceived as a normal part of ordinary family and community life.

Conclusion

This chapter has stressed the potential and actual conflict between helpers and those with whom they work. Whereas the dominant helper images are benign, the everyday experience of helpers is often dehumanising and unsatisfactory. Organisations of disabled people, people with HIV/AIDS, older people and mental health system survivors have come together in the 1990s, often to challenge the attitudes and practices of mainstream helping systems and to campaign for change. Key to this has been the provision of peer support and mutual aid: rather than relying on professionals or others who do not know what it is like to experience the situation, people learn from and rely on each other for advice and service. By becoming more informed and self-confident, people can demand their rights and better treatment. Moreover, organisations are ways for the voice of users to be heard within statutory and voluntary organisations, and play a role in advocating change in practice. Consumerism was a key element in the Conservative rhetoric of community care, and democratisation is part of the Labour repertoire of values: in practice, openings for consultation and participation have been brief and transitory. User involvement should become a key part of the setting of priorities and the delivery of services.

If organisations of the marginalised can become established, they may provide an effective counterweight for professional dominance. This might be a move towards the accountability of local authorities and of professional groupings. Statutory services are formally accountable through the processes of local democracy, but these can be inaccessible or difficult to affect from outside the system. But consultative procedures and the advocacy of organised user interests may lever change, in the way that, for example, police forces may be held to account through police authorities, community liaison and open meetings. The aim should be to achieve a partnership between helpers and those they help on a collective level, in order that individual encounters are made more humane and egalitarian. For

example, self-assessment by people who receive services could replace the 'expert' assessment of professional care-managers.

Professionals are here to stay.   Andre Gorz argues for the removal of status, stratification and hierarchy from specialisation:

'I have nothing against professionals. They will always be there. There will always be surgeons, for example. The only question is how we stop them forming a class or caste, how we stop them doing nothing but exercise and monopolise their skills, thus turning these into a source of power ' (Gorz, 1985,76)

Whatever its problems as a noun, 'professional' remains an adjective to aspire to. It suggests exacting standards of self-judgement, and values such as confidentiality, competence and trust. Perhaps the key to progress is reducing the gap between helper and helped. The origins of the word 'therapy', for instance, lie in the Greek *therapeuein,* meaning 'to accompany, to serve': this implies an empathy and shared endeavour in which helper and helped are open to change. Greater collective organisation and political strength of user constituencies will aid the balancing of power. But professionals will need to relinquish some of their status, and recognise the humanity and vulnerability which they share with the people for whom they work.

Albert Memmi asks what happens to the coloniser who refuses. They operate in a difficult position because they cannot escape from a concrete situation. But those who have historically dominated can contribute to a more equal relationship in future. After all, helpers themselves will inevitably need to be helped one day. Distinctions, such as separate toilets and canteens, should be removed, and with them the manner in which professionals provide help in ways that bolster their own status at the cost of those who are helped. David Brandon suggests that' *We can gain professional confidence and personal security at our consumer's expense – by taking over the running of his life' (1990, 40).* He also quotes a memorable phrase from Tolstoy: *'I sit on a man's back, choking him and making him carry me, and yet assure myself and others that I am very sorry for him and wish to ease his lot by all possible means – except by getting off is back'* (1990, 6).

Removing the distinctions and standing shoulder to shoulder is also about recognising the ways in which everyone -not just professionals - is a helper and a healer. Specialisation means that our everyday capacities and responsibilities for helping ourselves and others are denied, and the role is handed over to the professional doctor or social worker. User groups and mutual aid and support networks are ways in which the helped can themselves become helpers. We should not expect people in formal helping roles to achieve standards which we do not achieve ourselves. The listening which is key to real helping is a capacity which is open to everyone:

'Healing is the humble but also very demanding task of creating and offering a friendly empty space where strangers can reflect on their pain and suffering without fear, and find the confidence that makes them look for new ways right in the centre of their confusion.' (Nouwen, 1976,90)