

"PATIENT" EMPOWERMENT

WITH SPECIFIC REFERENCE TO DISABLED PEOPLE

A response to the Department of Health 'Patients Charter', 1992

1. INTRODUCTION

This paper represents the collective view of the Derbyshire Coalition of Disabled People. This means that the question of "patient" empowerment has been opened up to reflection and critical analysis by disabled people who have direct experience both as consumers of health services and as members of a group exposed to extensive discriminatory practices in many areas of social life. However, discussions have also taken place with non-disabled people, including service providers, as part of the process of developing ideas and testing conclusions.

The main areas of concern covered by this paper are set out below. They are written in the form of statements and/or recommendations. For each one of these to be properly addressed, the Coalition feels that major changes both in attitudes and in practice need to occur in the NHS, changes that give substance to the current progressive rhetoric.

2. TERMINOLOGY

2.1. The very phrase "*patient empowerment*" begs a number of questions concerning the distribution of power between those who use and those who provide health services. These questions have many dimensions - historical, economical, social and personal - and they revolve around the vulnerability of people who confess to be in some way sick in relation to those who profess in some way to cure.

2.2. Given the gradual historical accumulation of power by health practitioners, expressed through the acquisition of professional knowledge and control of health resources, the word 'patient' has become dis-empowering in the context of what is a very unequal relationship. Practitioners unconsciously reinforce the relative powerlessness of health service recipients through their thoughtless and generalised use of the term, especially when it is used in your own home when you are not sick. Many disabled people are not sick but still receive health services.

2.3. The implications of the use of generalised terms such as '*patient*', '*client*', '*consumer*', '*professional*' need to be thought through by all who use them. They are very powerful in defining relationships, too often in favour of the health worker.

2.4. People's own names should be used in the form they prefer - with no value judgement imposed when such a choice is made. People should not be referred to as "*dear*", "*love*", "*mum*" etc. Such terms may often seem to be culturally or colloquially appropriate, but their unconsidered or thoughtless use contributes to the process of de-personalisation and sense of powerlessness which has become part of NHS practice.

2.5. When discussing or referring to service users, the term 'it' is offensive, damaging and should be discontinued (particularly common among surgeons). It represents the epitome of de-humanisation of people seeking health care, and is a most inappropriate application of scientific pseudo-objectivity in context of a human desire to heal and be healed.

2.6. Similarly, no one should be referred to as if they are a condition, eg, "this *one's a Spina Bifida*". or "we've got a *back coming in today*"! The common use of such terms is only superficially innocuous: they form part of the many patterns of distancing which reinforce the controlling element of the health provider role. In turn they add to the process of power stripping of users, often already quite vulnerable merely by virtue of their physical or mental condition.

2.7. All staff, including medical staff should wear name badges and also introduce themselves clearly.

3. DE-HUMANISING PROCESS OF HOSPITAL ADMISSION

3.1. It will be clear from the points made above, that disabled people are only too aware of many of the negative processes at work within NHS practice. As we are admitted to hospital we are stripped of our possessions, our names, and identity' as an individual with rights and dignity. We believe the feeling of powerlessness engendered as a result does not contribute 'positively to either the psychological or physical well being of Health Service users.

3.2. People should be allowed to take and use their own wheelchair in hospital and whilst travelling on ambulances. Despite the enormous discomfort and distress of being deprived of one's own chair - and often one's own pressure relief cushion - after years of work this issue it is still unresolved. Disabled people and wheelchairs are NOT interchangeable. A person's wheelchair is intimate to posture, comfort, safety and identity. To remove it can produce an extreme sense of powerlessness, resentment and frustration.

3.3. The historical development of medical practice has resulted in the concentration of resources in many large, complex and impersonal buildings, the very size of which reflects the power and dominance of the profession vis-a-vis service users. Many people find these places intimidating and confusing, and these negative reactions are often compounded in the case of disabled people by poor design and other features. It is important that careful attention is given, in consultation with representative disabled people, to matters such as adjacent parking, arrangements which are welcoming and helpful to people with visual or hearing impairments, and to fixtures, fittings, aids and equipment which promote independent functioning rather than dependence on staff.

3.4. The removal of clothing, routinely, on admission to hospital is a frequent experience of disabled people, even though the subsequent medical examination may not require complete - or in some cases - even partial undressing. It is common knowledge that to be stripped of clothing is to be made ultimately vulnerable and powerless. In addition, for disabled people, undressing and dressing can be an extremely difficult, sometimes painful and often time consuming process. Careful thought needs to be given as to whether routine admission procedures of this kind are really appropriate. People should, if they so wish, be able to keep their own clothes and also use their own bedding if in hospital for a length of time.

3.5. People should be able to take their own pressure relieving equipment or any other helpful aids, including familiar continence equipment. Personal regimes of pressure sore prevention and continence care have in many cases been painstakingly worked out by disabled people over many years, and it is fundamental that these should be respected and adhered to by staff. The consequences of not working with the disabled person to her or his regime could have dire health consequences.

3.6. If people wish to exercise personal preferences related to any of the above they should be encouraged and not be seen to be implicitly criticising the standard of care available. Only by open exchanges of information and ideas can we reach a stage whereby our relative roles as "patient" and "*professional*" become complimentary rather than competitive.

3.7. Individuals' needs and preferences should be valued. In certain areas of knowledge, disabled people's understanding of their own bodies should be seen as superior to those of the medical staff. Should an individual care plan be drawn up, it should include the expertise of the disabled person and their family. The limitations of professional observations or empathy should be fully recognised by Health Service staff in planning any care regime.

3.8. In the case of mixed-sex wards, people should have the choice of not being allocated beds adjacent to people of the opposite sex. This choice is especially necessary where religious or cultural beliefs and customs suggest that the question of gender is important to the people concerned.

3.9. People's own expectations of degrees of privacy should be respected. It has been the experience of many Coalition members that their bodies have been exposed to other 'patients' and or visitors, or to people without direct involvement in their immediate health care needs either gratuitously or through carelessness by nurses, doctors and other staff. Such situations can produce extreme feelings of powerlessness, anger and resentment which are inimical to the healing process.

3.10. Relatives who would normally care for disabled people or for their children should be supported in providing the same care in hospital if they wish. This expertise is often wasted and dismissed by 'professionals'.

3.11. It is the experience of our members that the medical and related professions have generally adopted a view which extends beyond promoting good health, seeing successful outcomes in terms of restoring or rehabilitating 'patients' to some undefined state of able-bodied normality.. However, it is not necessarily the case that disabled people wish to have their bodies tinkered about with in order to conform to this view. A major education campaign needs to be developed to counter the predominant belief that being disabled is a personal tragedy to be avoided at all costs. This negative view of human difference translates into a loss of self-worth, and contributes significantly to the powerlessness of disabled people in health care settings. Such a campaign should include staff receiving extensive awareness and equality training by disabled people as part of their basic professional education.

4. EQUAL OPPORTUNITIES

4.1. The needs of Black disabled or other Black service users should not be assumed to be essentially the same as those of white service users. The services, aids and appliances provided to Health Service users should be examined in respect of racial differences.

4.2. The above comments apply similarly to women's needs. Our experience suggests race and gender discrimination is rife within the Health Service. Such discrimination is not only excluding at the level of 'patient' participation it also impedes the development of a representative workforce able to respond to the different physical and psychological needs of service users.

4.3. Service users with learning difficulties need to be valued as also having expertise regarding their own bodies and emotions. Difficulties in communicating with such service

users, or also in communicating with people with hearing and speech impairments, should be recognised as indicating an unmet training need on the part of the Health Service and not as a failure on the part of the individual.

4.4. A significant sense of loss of control frequently accompanies situations where staff automatically assume that the physical needs of service users who have had or are having contact with the Mental Health system are inextricably linked with their emotional or intellectual "health". Such assumptions can be very damaging and imply a lack of professional objectivity in the absence of appropriate evidence.

4.5. Special care needs to be taken to ensure the emotional and intellectual difficulties experienced by some disabled service users are not treated in a dismissive or cursory way, eg, dismissed with a bottle of pills. Similarly, emotional and intellectual difficulties should not be dismissed with comments such as "*Well, it's your age*" or "*All you need is to find a job,*". Each of the above points in this section, if not noted and acted upon, can lead to a substantial loss of confidence in the Health Service accompanied by a sense of powerlessness in the individual.

5. INFORMATION

5.1. People should have easy access to information kept about them and be helped to understand it. This includes accommodating the informational needs of those for whom English is not a first language.

5.2. Staff need to be empowered to share such information and help people understand it. We acknowledge that sharing power is risky for staff and they need to be confident that they will be supported.

5.3. Information about treatment and its possible side-effects should be given to people as of right. They should have the choice to decline such treatment without losing access to all other services as a result.

5.4. Copies of information about or for the use of individuals should be made available to them, in a form appropriate to their requirements, e.g, in large print, braille or on tape. This approach facilitates a clearer understanding, promotes confidence in disabled service users - and should go some way towards ensuring that speculative and judgmental comments are more carefully considered before being committed to paper.

5.5. When dealing with people with any degree of deafness or blindness it is necessary to ensure appropriate formats of communication (including BSL interpreters) are used to facilitate an exchange of information.

6. COMMUNICATION, CONSULTATION AND PARTNERSHIP

6.1. People should be able to choose whether they themselves, and/or a member of their family, and/or an advocate or supporter of their own personal choice attend meetings regarding them, who can then tell them all that was discussed if this is what they require or prefer. If a person's impairment makes it difficult or impossible to exercise such a choice, the decision about how best to proceed should be collectively taken, normally involving the immediate next of kin together with any appropriate advocate. Where family conflicts exist, these should be dealt with outside any case conference, thus avoiding additional trauma for

the disabled person in what is usually a difficult situation accompanied by acute anxiety and powerlessness.

6.2. It needs to be recognised that case conferences, usually over-weighted by professional staff, can be very intimidating affairs. To most "patients" and their supporters they can be unfamiliar and overpowering, and this inhibits openness, communication, understanding, confidence and trust. Multi-disciplinary team work may well have become an accepted part of hospital practice, but it needs to change to meet the real needs of those it purports to serve. In our view, it should extend beyond the hospital itself into partnership with people and agencies in the community outside. Good partnerships depend on mutual trust, and this above all must extend to disabled people themselves, their families, personal assistants and advocates. The ultimate aim must be to ensure the best possible outcome for all hospital "patients" without discrimination and without disruption as they move between hospital and community.

6.3. A further advance towards the empowerment of "patients" would in our view come through an extension of peer counseling within health settings. The Coalition is aware from its own experience that peer counseling is an important part of the process by which many disabled people successfully respond in a positive way to the changes in their lives brought about by illness, injury etc. One element of this beneficial process is often an empowering sense of direction and control in the life of the person concerned.

6.4. Staff acting as advocates for disabled people should not be subjected to retribution if their view does not conform to the view of other professionals.

6.5. People should be asked in private, and in good time, whether they object to students or other non-related staff being present at consultations, operations or during childbirth. If students are present people should not be left guessing along with the students as to the cause or prognosis of their illness where the Consultant is aware of it all along.

7. TERMINAL ILLNESS

7. 1. Extensive training, at all levels of medical, support staff should be made compulsory on the issue of imparting information about or supporting people through terminal illness. In disabled people's experience, in common with relatives and health workers, it is an area fraught with ethical and personal difficulty. A sense of powerlessness can affect everyone involved which, in our view, can only be addressed in a mutually supportive, open, and sensitive way. A particular difficulty which has fallen within the experience of our members has been where there has been a loss of clarity with regard to whose feelings should be most respected. The central issue, in our view, is to clearly distinguish, respect and support the feelings and wishes of the person with a terminal illness, as distinct from those of family or close friends (who may themselves need support, but perhaps in a different way). An additional dimension of powerlessness can be experienced where this sense of clarity has been missing. Where the views of the 'patient' are difficult or impossible to elucidate, or where questions involving the use of life support systems are raised, decisions should not in our view reside solely within the Health Authority, but should be tackled in a multi-disciplinary way, with due regard given to the points raised in section 6 above.

7.2. People have a right to know that they are dying: denial of this right can be accompanied by an acute sense of powerlessness. Time and again within our experience the feelings of relatives and staff dominate the decision making process about imparting the information. It appears to us to be morally wrong for the medical ' staff, the therapist, the nurses, and social

workers and possibly the family to all know that someone is going to die - and for the person concerned to be kept incomplete or comparative ignorance of the fact.

8. CONFLICTS OF OPINION

8. 1. Staff should be supported to accept that they can make mistakes, and that if they do they should apologise to the person concerned. This would be one of the most effective ways of beginning a process of empowering users of Health Services.

8.2. One of the most persistent themes within the Coalition's experience is where staff control outcomes, for instance by withholding, reducing or delaying the provision of services, by means of them holding "we know best" attitudes. This usually arises where a disabled person's knowledge about their own needs, or their own preferences regarding outcomes, which may sometimes be articulated by relatives, conflict with the perceptions of staff. Staff behaviour in these situations usually involves them in making pre-judgments about a person's needs and preferences, often at a stage when the person concerned may be emotionally sensitive and vulnerable. This behaviour can sometimes be subtly expressed and difficult to quantify, but can nonetheless; be adversely controlling and undermining of good health care and recovery. The effect of this usually skews the person's perception of the care they have received, with a sense of loss of control - sometimes tangibly expressed through the withholding of services - becoming the main focus of their memories.

9. ADDITIONAL SUGGESTIONS FOR IMPROVEMENTS

9.1. Users of health services should be represented at all levels of the policy making and planning of those services, and this approach should be formally built into the decision making structure. The direct experience of representative disabled service users, who are accountable back to their own organisations, should become a valued part of the structure with proper status within it.

9.2. Disabled people should be employed in far greater numbers and at all levels of the Health Service: a practical step forward would be for Authorities to stop applying for exemption from the 1944 Disabled Persons' Employment Act.

9.3. Advocates for disabled people should be trained and available to anyone who does not feel able to represent themselves at case conferences etc. Advocates should be drawn from a wide variety of people to ensure that appropriate race and gender representation is also available.

9.4. A national training programme for staff which tackles all the empowering issues above needs to be devised in consultation with representative disabled people and centrally funded. It should include a majority of service users on its governing body. A suitable title might be "It **could** be you ..

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