

Discourses and Narratives Surrounding Disabled People in Hospital

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Abstract

Disabled people constitute a minority of patients in the normal hospital ward. They may belong to groups which often have their own ideologies or languages. Discourse is chosen here as a way of understanding the conflicts which may arise between disabled patients and the medical profession who emanate from two distinct 'epistemic communities.' The unsettling discourse of disabled people in hospital may centre on current medical practices, the shortcomings of the DDA or confused diagnosis. The work of Hauerwas on narrative theology is recommended as tool for the chaplain endeavouring to understand the situation.

Key Words: Narrative Theology, Disability, Language, Discourse, Chaplaincy

Disabled people constitute a minority of patients in the normal hospital ward. Of course there are specialist hospitals where spinal injuries are treated or which specialise in rehabilitation or certain forms of surgery. My competence does not extend to patients with learning difficulties or mental illness; although Hauerwas devoted a major work to the former in developing his narrative theology (Hauerwas 1986) which occupies a large part of this paper. This paper does not examine the types of communities which are found in these types of units; but will rather concentrate on the disabled person in, possibly, a minority of one in any type of ward where shared values cannot be assumed.

Before continuing, I should add that I visited the Chicago Rehabilitation Centre in 1991 where one is impressed by the specialist training offered to hospital chaplains who wish to devote their careers to this field. They, indeed, belonged to separate professional bodies. What is assumed in this paper is that all groups who have a common interest or background tend to use the same language or discourse to which others may not be privy through no fault of their own. Disabled people belong to groups which often have their own ideologies or languages. Much attention will be given to the ideologies of disability later but consider for a moment the fact that deaf people enjoy different signing languages and dialects which an amateur signer cannot hope to enter.

The Meaning of Discourse

Discourse is the use of language in either verbal or textual form to express material which has some social origin. Discourse in a technical sense implies social constructs and in the description of

discourse social change may be identified. Fairclough puts it thus:

In using the term 'discourse,' I am proposing to regard language use as a form of social practice, rather than a purely individual activity or a reflex of situational variables. (Fairclough 1992)

Fairclough argues earlier that some forms of discourse analysis are purely descriptive, whilst others reflect the social conditions which produce them. The result is that he views social change in the ways in which discourse practices intermingle and change. Finally, he suggests that discourse may be used to describe the appropriate sets of linguistic tools in a certain area of interest, such as medicine or theology. In sociology there was a movement from a theory of action to a discursive approach which considered that discourse revealed behaviour within the constraints of systems. Blimes sought to document this development of discursive sociology and to defend the new emphasis of the late Sixties. (Blimes 1986) Hidden within this new connection between systems and discourse is of course the implication that discourse inevitably reveals and reflects power struggles. So, discourse may be defined as text or speech which is addressed to an epistemic community whether that be the entire readership of a newspaper or the specialised talk of a medical seminar. It must be intentional and structured in some way which can be interpreted. Appleby et al defined discourse thus:

The use of language in speech or text in which the meaning of the words are specific to the community of users. (Appleby 1996)

Potential sources of discursive conflict

Several key words appeared in this discursus into the meaning of discourse which indicate the main players in this paper. First, images of disability may result in "social constructs" which are of limited value and are often dysfunctional. Second, discourse represents professional language and standards which affect interaction with disabled people. Last, "epistemic communities" usually imply ideology, in this case that of some disabled people.

Before continuing we must examine the physical situation in a modern hospital. Staff shortages mean that basic tasks such as feeding and finding two nurses for one bath is an impossibility. If a disabled patient is admitted for day surgery, there will be a requirement for procedures which will normally be unnecessary -- the patient may require to be undressed by a nurse. I am currently awaiting a minor investigation which would not normally involve a general anaesthetic but must now join a longer waiting list because of this extra requirement. Many wards are open for five days only and equipment is automatically reduced with the probable result that there will be no lifting equipment nor accessible toilets. All these changes compound the alienation which the disabled patient may feel. This is reinforced by the natural tendency of vulnerable patients to become obsessed by seemingly little things such as food, noise or the irritating habits of an individual nurse. (Morrison 1994) If these matters are of such importance to the average patient, how much more must the disabled patient have to talk about when the above deficiencies begin to frustrate her?

Bury characterises the situation of a disabled person as someone suffering "biographical disruption" (Bury 1982) which inevitably sets a different agenda for both the both and the medical staff. Mary McClymont comments on the implications of biographical disruption thus:

Adults are accorded rights, but carry heavy responsibilities. They are expected to be physically fit, provide for their families, contribute to their community, achieve self-fulfilment and facilitate this for others. (McClymont 1992)

The implication is that the disabled patient brings with him a series of problems which are not normally catered for in a general ward and may be found lacking in some of the expectations staff will have of their average patient. The corollary may also pertain -- the experience of disability may have been a frustrating or anger-producing

one which has resulted in an obsessive concern for disabled rights and the non-violation rights which have been gained through campaigning all of which may count for naught in the over-stretched hospital environment.

Is there a corpus of literature which deals with disabled patient in a normal hospital setting? There are identifiable groups within hospitals which generate discourse in journals and nursing magazines. Palliative care and the care of the elderly are obvious examples, but electronic searches of literature reveal that the people with learning disabilities receive much attention either as problems or as potential victims of abuse. (McCarthy 1992, O'Niell, 1991) The literature about nursing disabled or chronically ill people tends to concentrate either on rehabilitation or long-term home care. King, for instance, offers considerable insight into the difficulties of long-term care in terms of family counselling and enabling disabled patients to take control of their lives, but does not offer any advice on general nursing in a normal hospital ward. (King 1985) Gibbon comes nearer to identifying the heart of this paper's problem by studying stroke patients as a group in a general ward setting. (Gibbon 1991) Here we want to ask what happens to the disabled person when they become patients in a general ward which may well not be geared up to meet their requirements and where they will encounter medical and nursing staff who as ill-equipped to meet the extra needs of their disability.

The Scottish Hospital Advisory Service (SHAS) has a section dealing with disability issues, but Dr Margaret Whoriskey states that whilst research has been undertaken about people with learning difficulties, work on people with physical disabilities will only begin this Spring and will consist of a series of dedicated visits to services for the physically disabled. This will not cover general hospital facilities and is therefore unlikely to address the issues of this paper and the related discourse. She writes that most research on disability has previously examined the issues of ageing and have lacked 'a specific focus.' (Author's personal enquiries) It would appear that this influential body as not yet tackled the major issues surrounding the Disability Discrimination Act. Should this be the case it is indicative of an adherence to the medical model of disability. It might also suggest that the implementation of the DDA is further down the agenda than the legislation permits.

The NHS has until October of this year to implement Section 21 of the Disabled Discrimination Act 1995 (DDA), and has been holding consultations throughout England over the last eighteen months. I attended a seminar at the Scottish Office

in January. Basically, the Section deals with the provision of 'goods and services,' and begins:

Where a provider of services has a practice, policy or procedure which makes it impossible or unreasonably difficult for disabled persons to make use of a service which he provides, or is prepared to provide, to other members of the public, it is his duty to take such steps as it is reasonable, in all the circumstances of the case, for him to have to take in order to change that practice, policy or procedure so that it no longer has that effect.

This is going to require that hospitals make their practices accessible to disabled people, in part by altering premises, but also medical practices. To offer two examples from the seminar:

- 1) It is nursing practice to move patients further from the nursing station as they improve. This means that a blind person must re-learn the routes to the toilets every time she is moved.
- 2) A man with learning difficulties missed appointments at the 'blood clinic' because in following the signs, he walked past the 'haematology unit.' Access is not only about wheelchair ramps, but about, for example, practices and co-ordination of correspondence and signage.

The DDA, with its greater empowerment later this year by the establishment of the Disability Rights Commission, already provides a discourse with which disabled people can criticise the NHS. The legislation lays down not only a benchmark of good practice; but also a weapon, sometimes admittedly blunt, with which to threaten or change current routines within hospitals. In rehabilitation wards and hospitals, one would expect to have evidence of compliance for the benefit of disabled patients, but no such awareness may be evinced in a general hospital.

Occupational Therapists, Speech Therapists and Physiotherapists are faced with a different set of dilemmas when treating a disabled patient in a general setting. Their main areas of work tend to be with the discharge of elderly patients from much needed beds into the rigours and dangers of their once benign homes. These patients do need all the help which can be offered, and, despite frustrations and resentments, they will gratefully accept what is offered. Disabled clients on the other hand understand the workings of the Chronically Sick And Disabled Persons Act 1970 (Extended To Scotland 1972) and have already

experienced the prevarication's of social work departments scrapped for cash and manpower.

Occupational Therapists have a natural instinct to provide the best and most enabling equipment for disabled clients and have an instant rapport with such people. However, there is an explosive conflict between their professional knowledge and the amateur knowledge of the client which complicates the caring relationship. The disabled patient or relative is either very well informed or finds herself in informed conflict with the OT. Nursing professionals have found this relationship difficult and usually blame conflict upon the reactionary or protective attitude of carers and their relatives. (King 1985) There can be a real dread of the medical model as represented by OT meeting the social model of the disabled client head-on.

These models conflict in that the social emphasises the right of the disabled person in the community, in a society which has constructed disabling structures, intentionally or otherwise. The model has the drawback of either being based on Marxist or conspiracy theory which may lead to a lot of resentment. (Barton 1996) The medical model seeks to solve a medical problem which may be unrelated to the social circumstances of the person. In fact, the hospital by its very definition represents the essence a medical model.

Narrative theology

Hauerwas provides a theological key to the study of peer group discourse when he considers the discourse surrounding children who are terminally ill. (Hauerwas 1993) Hauerwas' main concern is with the way children overcome the obsessive secrecy with which medical staff and parents attempt to shield them from the dreadful truth of their situation. The curiosity of the children and their solidarity in the face of adversity suggests that the attempts by the medical profession to control their information and to gain the passive co-operation of their parents is an activity where medicine not only fails but offers the wrong solutions. The medical profession does not have the ability or right to offer a complete panacea of care which stretches beyond their professional competence.

Chaplains have the ability to offer patients control in the appropriate areas of emotional development and spirituality. This, of course, is highlighted by conditions and diseases where there can often be a conspiracy of silence and resultant discomfort on both sides. Chaplains are well aware of these difficulties. Whether medicine is dealing with the problems of ageing or terminal cancer, people must be equipped with a narrative which ade-

quately deals with the areas where medicine must remain silent.

Put in the language of theodicy, we now suffer from the means we tried to use to eliminate suffering. (Hauerwas 1986 p. 108)

Medicine is like theodicy, it must produce answers to its own lack of omnipotence just as theology must tackle the problem of evil. Communities, such as a children's ward, AIDS clinic or geriatric unit must produce the narrative which overcomes our awareness of medicine's inadequacies. What the previous sections on disability discourse described was the conflict faced by medicine and its institutions when the intractable, and probably incurable, nature of disability comes up against the general competence of medical procedures in the general ward setting.

Thus we may begin to unravel the task of the Chaplain when confronted with an angry or frustrated patient who is disabled and knowledgeable in the field of disability. There will be three elements in any discourse which the patient may have. 1. The patient is ill and is concerned about the ailment as any other patient might be. 2. She will be frustrated by the disabling factors in the ward and hospital. These may be of a physical nature in the layout, or technological, or attitudinal. Examples of staff attitudes leading to difficulties have been quoted above. 3. She will be aware of the shortcomings in the fulfilment of the law and codes of practice which are intended to improve the service offered to disabled patients. The object of the Chaplain must be to understand the interplay of these three elements and to see the patient has a whole person.

This last sentence contains the biggest cliché which may be uttered in this type of journal. Hauerwas is well aware of the problems surrounding such. Glib assertions about the "whole person" masks the basic problem of accepting the narrative of the patient as a complete reaction to the medical situation. Put differently, it is the difference between acquiescing to the medical model of disability which physicians favour, and the social model, however defective, which has become ingrained in the patient's psyche.

... narrative is the characteristic form of our awareness of ourselves as historical beings who must give an account of the purposive relation between temporally discrete realities. (Hauerwas 1983)

Quoting several sources from Hauerwas is to emphasise the importance of narrative theology in helping chaplains to identify the true plight of a

patient. It is the release of their emotions and thoughts which may return wholeness not a promise on the part of the medical profession to consider the "whole person." In his book on disabled people with learning difficulties, *Suffering Presence*, Hauerwas rejects the medical profession's concern for the "whole person" as the "resacralizing" of medicine (Hauerwas 1986 p. 69) and in this context the release of narrative is to be commended as a means of allowing the disabled patient to express his total [whole] concerns.

Having suggested how the Chaplain should approach the patient, what about the staff. First, the staff have new roles to find in accommodating their disabled patient into their current work practices and their view of illness. Second, some of the physical barriers must be removed and compliance with the law sought. Finally, disability must not be inappropriately regarded as symptomatic of a general illness but as a characteristic of the patient which has moulded her background and personality. The disabled patient and hard-pressed staff may have different agendas, and so the Chaplain must seek to interpret the problems to both parties in a dispassionate way.

Finally, it must never be forgotten that there is a theological project in all this activity. Dealing with physical barriers and with the views of the disabled patient may appear as a very secular activity; yet as we have shown, there can be a commitment to the qualitative and spiritual growth of the individual. It may be a lasting and unique experience to find someone who is prepared to integrate the various discourses into a coherent whole devoid of the anger which comes from fragmentation of the person's narrative.

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