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A critique of models of disability; their influence in nursing and potential role in challenging discrimination

INTRODUCTION

In a recent report a UK government minister has gone on record as saying "we have got to move away from the medical model" (Joint Committee on Human Rights 2008, p.57-58). Such statements must be set in context and this record is found in a Joint Committee on Human Rights report which focused on adults with learning disabilities. The injunction was to apply the medical model only in the context of illness, and not to the whole life of all disabled people as if they were perpetual patients. The report was published in early 2008 and described recent experiences of adults with learning disabilities in contemporary Britain. Within all spheres; including health and residential settings, there was evidence of discrimination and abuse. Elsewhere disturbing parallels have been drawn between the cultural mind set which almost legitimizes and sustains this behaviour in contemporary Britain and the extermination of disabled people during the Second World War (Gallagher 2001). That analysis points to the operation of an underlying regime which fails to afford disabled people equal value as citizens (Scullion 2008a). Disability discrimination crosses national boundaries making this an issue of global significance.

This paper examines the experience of disabled people not exclusively those with learning disabilities. It explores models of disability and pursues the claim that we must move away from a medical model beyond the politicized context of government reports (Joint Committee on Human

Rights 2008). The potential for nurses to either sustain or challenge disability inequalities makes models of disability very relevant to the nursing profession and its many 'disabled' clients. The basic thesis developed is that nurses' thinking; conceptualization or model of 'disability', and values which consistently stem from these, have a tremendous impact on their engagement with disabled citizens. This analysis argues the case for nursing to move away from a medical model and towards a social model of disability as a way of challenging discriminatory thinking and actions.

BACKGROUND

The concept 'disability' is contested. This fuels contentions over models of disability. However dominant definitions subscribed to by medicalised professionals and legal bodies will find many commonalities with that enshrined in current UK legislation;

“someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” (Direct Gov 2007).

Such definitions may include people diagnosed with Cancer or HIV even where adverse effects are not apparent. This comprehensive and inclusive approach embraces people with learning disabilities, people with mental health issues as well as millions of citizens with other impairments. All health professionals; nurses in all disciplines and departments will therefore have frequent contact with disabled citizens. Far from implying that this frequency of contact suggests that being disabled is akin to being ill, it is more a case that this characteristic is so common that nurses inevitably see disabled people within a typical caseload. Since most people who are classified as

'disabled' have acquired impairments rather than congenital impairments, inevitability contact with health services and nurses is apparent around the time of onset, which is perhaps a vulnerable and transitional time in their lives. In some cases contact continues for many years. The person who has a moderately severe head injury will, for a period, have regular contact with acute and then rehabilitation services. They may then emerge with an altered self-image many months or years later, having traversed from 'victim', through 'patient' to 'disabled person' (Morse and O'Brien 1995). Along with the majority of the population, such citizens have contact with professional nursing services for advice or screening, most of which is entirely unrelated to their ongoing impairment or medicalised label. While their status as 'disabled person' is no justification for discriminatory denial of human rights, such experiences are frequently reported (Scullion 2008b).

DATA SOURCES

Building on previous work by this author, literature was obtained using databases; Psych-INFO, Medline and CINAHL from the year 2000 to 2009, using derivatives of the concept 'disability', associated 'models' and combined with 'nursing'.

DISCUSSION

The concept 'disability'

'Disability' has traditionally been viewed within general nursing as a medical condition or illness which amounts to a deviation from biological or social norms resulting in dependency (Scullion 1999a, Murphy et-al. 2007). Recently nursing papers on the theme of 'disability' have focused on functional restrictions (Pellatt 2005, Gill et al. 2006), illness and measuring various impairments, (Cabrero-Garcia and Lopez-Pina 2008, Kun-Yang et al. 2008) and quality of life linked to age-related impairments (Murphy et-al. 2009), suggesting that a firmly medicalised notion of 'disability' retains dominance. Replacing the word 'disability' with 'illness' in many such papers would keep the authors' intended meaning entirely intact. In mental health nursing however there is a growing interest in the possibility of utilizing the social model of disability in developing a social model of mental health (Beresford 2004). Learning disability nursing leads this challenge to medicalisation, having acknowledged that for its clients discriminatory denial of human rights is commonplace (Camus 2008). There are few advocates for adopting a social model of disability and a rights-based approach to care and the generation of nursing knowledge (Northway 2000, Northway et al. 2001). In adult general nursing there are very few champions who share a vision of tackling disability discrimination by using the social model of disability for education, research or nursing practice (Marks 2000, Wright 2001, Brothers et al. 2002, Spain 2008). One recent review by authors based in Canada (Boyles et-al. 2008, p.434), concluded that their results "illustrate the multiple theoretical and limited research understandings of disability". Yet in reviewing how 'disability' is represented in nursing and healthcare literature they present an argument for nursing to expand its understanding to embrace a social perspective on disability.

Although disability remains a concept that is viewed primarily as bodily restrictions (Shilling 2003, Cregan 2006) and almost synonymous with illness (Scullion 1999a), what has come to be

known as the 'social model of disability' is beginning to find a place in the nursing literature (Seccombe 2007a) and some are advocating a radical re-conceptualization of disability for nursing and nurses (Lee and Scullion 2001). Boyles et al. (2008, p.434) review of the literature firmly acknowledges that the way in which 'disability' is conceptualized and understood "greatly affects the emergence of health and social policies". Current evidence tends to support a hypothesis that nursing plays a role in inadvertent disability discrimination (Evans 2005, Marks 2007).

Medical model of disability

Implied within the call to move away from the medical model of disability is a stance suggesting that the impact of conceptualizing disability emerging from this paradigm is itself disabling (Whitehead 2006). In brief, this paradigm places the cause of 'disability' with the individual. That individuals affected should be referred to as 'patients' is no mistake, nor is it challenged. Since causes of disability; consisting of medical conditions, impairments of bodily systems or functions, be they traumatic or congenital in origin, are viewed as essentially akin to illness. Hughes (2000) claims that the impact of the medical model of disability is far from benign and there is evidence to support the notion that an exclusively medicalised notion of disability is pathological in its effect. There is a body of literature which demonstrates that a common experience of disabled people is that they face various kinds of discrimination (Barnes 1992, Gallagher 2001, Buzio et al. 2002, Thomas 2004, Smith 2005, Swain 2006, Vanhala 2006), even within health care settings, (Carter and Harrison 1999, Scullion 1999b, 2000a, Markham 2001, Brett 2002, Bowers 2003, Northway 2003, Pellatt 2005, Scullion 2008a).

Disability as a personal problem

Galvin (2005, p.398), a disabled person himself, researched the impact of the medicalised 'disability' labels and found that these became the "primary mode of identification". Furthermore the negative self perception of people who have acquired impairments is largely attributable to negative attitudes. It is acknowledged that during the transitional period, in the vulnerable role of 'patient', the medicalised professions, including nursing, have a powerful impact on the individuals' self-image. Galvin (2005, p.398) found that its impact was effected by "imposing a diminished sense of self", and that disabled people in his study who continued to *feel* disabled over time, did so because they were "trapped in the individualistic view that disability is a personal problem" (Galvin, 2005, p.409); that is the medical model.

Undermining and alienating effects

Furthermore the medical model has created an environment which promotes such a devaluation of the worth and citizenship of people on the basis of their disability status, health professionals expect people to 'blend in' and be as conventional as possible. Indeed the notion of 'normalization' in the field of learning disability rewards such behaviours as conditional to social acceptance. According to the analysis of Stalker et al (1999, p.7) this amounts to encouraging people to assume the values of those who devalue them such that "normalization can, ironically, be seen as itself devaluing disabled people". Keeness to de-emphasize differences gives rise to official reports taking such titles as 'a life like any other'. This appears to deny uniqueness,

differences in needs and the requirement for some adjustments by nursing services in their approach to disabled people when they become legitimate clients or patients.

Invalidation and abuse

Since the focus of disability within the medical paradigm rests with the individual who appears different when compared to socially determined norms, or the individual's pre-impairment state, the medical gaze is seen as a key player in invalidating non-conforming bodies (Hughes 2000). This process of invalidation of the bodies and lives of disabled people (Edwards and Imrie 2003), also paves the way for institutionalized disability and abuse of clients (Oliver 1984, Barnes 1992, Jenkins and Davies 2006) which ultimately involves the denial of human rights (Scullion 2008b). The term 'abuse' is used to embrace the concept 'maltreatment' which has been defined as harm via health providers, with or without intention (Hassouneh-Phillips et al. 2005). 'Diagnostic overshadowing', the process whereby medical personnel are so overwhelmed by the clients' 'disabled' identity along with the accompanying negative mind set (Mason and Scior 2004), becomes an additional barrier to healthcare when it is required by disabled people (Drainoni et al. 2006). Failure to provide healthcare when required is itself a form of abuse.

Fyson and Kitson (2007), who offer an insightful analysis of recent institutionalized abuse of disabled people within the UK, had to admit that these scandals were to be welcomed as 'progress' in comparison to the abuses of recent decades where the nature and extent of the abuse was more horrific. They conclude that such scandals, when uncovered, do not easily achieve newsworthiness because of the widespread acceptance of the disabled life as a devalued life, but that they do act as

drivers for change. Yet the government led report on recent scandals highlights abuse by professional carers who believed they were in the right and did not understand that their actions constituted abuse (Joint Committee on Human Rights 2008). This perhaps is one of the most distressing and worrying aspects of the report yet it can be traced to the prevailing atmosphere, certainly unchallenged and arguably sustained by the medical model. Scullion (2008a, p.354) suggests that conditions where discrimination against disabled citizens in many spheres of life is tolerated, including healthcare, is strongly suggestive of an underlying society which fails “to afford disabled people equal value as citizens”.

Unequal opportunities

The fact that disability was not recognized as an equal opportunity issue within nursing at the turn of the century (El Ansari 2002) was doubtless a reflection of the slowly unfolding provisions of the Disability Discrimination Act [1995] in the UK. The Disability Discrimination Act is not mentioned in UK regulations and guidance governing nursing prior to 2006 (Sin & Fong 2008). Perhaps of greater impact was the dominance of the medical model playing a key role in suppressing even the inclination to challenge the status quo. ‘Disability’ cannot comfortably be conceptualized as both ‘illness’ and an ‘equal opportunity issue’ without provoking cognitive dissonance which demands a resolution. However If disabled women are to experience less abuse at the hands of health professionals (Hassouneh-Phillips et al. 2005), if the rapidly developing genetics knowledge is not to be used in discriminatory ways against disabled people (Newell 2000) and if disabled people are going to find acceptance as members of the nursing profession (Marks 2007), then a move away from the medical model is necessary.

Moving away from the medical model

If this conceptual model contributes to discriminatory thinking and the development of a negative and discriminatory professional mind-set (Hughes 2000), nursing must challenge and distance itself from the medical model (Scullion 1999b, 2000b). Some argue quite directly that the medical profession and others, including nursing, are responsible for the majority of the negative discriminatory experiences which disabled people have (Gallagher 2001, Williams and Heslop 2005, Barnes 2007). Others suggest that since the paradigm is dominant, its dominance stretches beyond the health professions making disability a much wider social, ethical and political issue (Barnes 1992, Crow et al. 1996, Beresford 2004, Ghai 2007, Hirskey 2007). On the basis of this analysis nurses should become much more aware of their conceptualization of disability, its underpinning model of disability and their practice when dealing with disabled people as clients, some of whom will be especially vulnerable. Goodall (1995), a nurse who identifies himself as a disabled person, argues that nurses must apply medical ideas in the narrow confines of its remit and in appropriate circumstances only. He argues that nursing, and other medicalised professions, do have a legitimate role in assisting some disabled people, who may have a need of expert management of pain or other symptoms such as spasticity, but that the medical model alone is unhelpful.

Social model of disability

The social model of disability is located at the opposite end of the philosophical continuum from the medical model. In brief it has emerged from institutionalized disabled people as a result of their analysis of their experiences mediated largely via the dominant medical model. This paradigm sets the responsibility for the discriminatory life experiences of disabled people firmly in the lap of society (Oliver 1984). Disability is not caused by the individuals' impairments; rather it implicates collective thinking which excludes and devalues disabled people. Disabled people have defined 'disability' as the disadvantage or restriction caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. Steps present insurmountable physical barriers to some people. Barriers may also be educational, economic or attitudinal. Poor expectations by teachers and segregated education give rise to educational attainments which are lower than average and do not allow individuals to reach their own potential (Schriner 2001, Miller et al. 2004). This in turn contributes to higher unemployment and employment within lower income sectors in comparison with non-disabled people. Access to health care information and facilities is similarly restricted because of policies, practices, negative assumptions or diagnostic overshadowing, which further excludes disabled people. The powerful institution of medicine, including nursing by association, is reserved for particular criticism since it is cast as the arch enemy of disabled people in sustaining the disempowering medical model and is, according to Goble (2008), a key player in the oppression of disabled people.

Impact and implications of the social model

Around a decade has passed since calls began to be made within the nursing literature to recognize the social and equality dimensions of disability, accept the reality of disability discrimination within general nursing and to consider the potential of the social model to remedy this situation (Northway and Thomas 1999, Scullion 1999a,b, Stalker et al. 1999, Marks 2000, Northway 2000, Scullion 2000a,b,c). A recent review confirms that this call for nurses to accept the social dimensions of disability has gone largely unheeded (Boyles et al. 2008). It is claimed that the social model holds the potential to “alter societal perceptions of disability” (Bricher 2000, p.781) and to “have a positive impact on service models and policies” (Boyles et al. 2008, p.435). Goals which will be hindered without improved dissemination and recognition of the social model which Bricher (2000) and Scullion (2008a) argue is especially necessary within general nursing.

There are some indications that nurses, beyond the mental health and learning disability branches, are beginning to respond to the challenge disability discrimination presents to the profession. This may be traced to a growing understanding and acceptance of the social model and its relevance to nursing and its patients or clients. After conducting extensive research across ethnic, national and racial boundaries, Pfeiffer (2003), a well respected researcher and disability scholar, has concluded that being a disabled person almost universally confers low social status. In view of this and the difficulty in piercing the paradigmatic shell of the established medical model it is hardly surprising to note that the social model is not prominent in nursing literature (Boyles et al. 2008) and its impact is, at best, embryonic and negligible. Nevertheless there are examples, from the spheres of nursing practice and education, where there is evidence of some direct or indirect influence of the social model and a growing recognition of its potential to drive changes.

Nursing practice

Buzio et al. (2002), who explored the Australian in-patient experiences of people with Cerebral Palsy, found that specific impairment related needs were not being met, which they point out, represents a standard below legal requirements. However this study referred to the social model only by way of background to acknowledge that disabled people may be given lower priority than non-disabled people in the provision of health care, a situation they attribute to a knowledge deficit. Although the model in operation was not explicitly explored it clearly did not result in disabled people receiving their rights, while they were patients.

Pellatt (2005), in a UK based qualitative study, examined the concept of rehabilitation in relation to spinal cord injury. While the important influential role of rehabilitation nurses and others is recognized since they convey professional expectations and values, the concept of disability in operation appears firmly based on the medical model. Rehabilitation is initially defined as 'teaching people to live with their disability', thus locating the problem at the level of physical impairment. 'Disability' is seen as equivalent to impairment and described as 'suffering' while the person retains the title 'patient' during their entire post-spinal injury life. Yet of the three major ways of viewing rehabilitation, one of these, entitled 'empowerment', shares some ideas with the social model, at least in recognizing the imbalance in power relationship between professionals and disabled patients.

Harrison and Berry (2005) describe their attempt to improve the life chances and health of people with learning disabilities by addressing their need for mainstreamed primary care in the UK.

They particularly promote a shared approach between the learning disability services and mainstream nursing and primary health care services, suggesting that this need for a shared perspective would be facilitated by adopting the social model. In so doing they predict that health needs assessments and health action plans for individuals with learning disabilities will be more effective, reducing health inequalities.

The profession is opening up to retain nurses who acquire impairments and thus become disabled people during their career (Department of Health 2000, Scullion and Jayram 2000, NHS Direct 2008) and even allowing disabled people who would never have considered nursing as a career or would have been rejected at the application stage, to enter training (Scullion 2000b, Carroll 2004, Evans 2005, Seccombe 2007b, NHS Direct 2008, Spain 2008).

Role and implications for nurse education

While it is claimed that nursing curricula are beginning to be influenced by equal opportunity issues (Bheenuck et al. 2007), and that nursing has engaged with human difference (Peckover and Chidlaw 2007), disability does not feature prominently within these initiatives (Scullion 2008a,b). The UK Royal College of Nursing (2007) has recently promoted an 'equalities champion' role, encouraging nurses to 'become the solution' to inequalities identified within their locality. While this provides evidence that nursing has embraced the inequalities agenda, prevailing conceptualizations of 'disability' tend to exclude it even from this agenda, with only learning disabilities receiving attention within their campaign. In general nursing curricula, disability was found to be conceptualized as deviation or dependence and the social model held no credibility towards the end

of the last century (Scullion 1999a). 'Disability' retains the position of inequality amongst the inequalities. The recent conclusion of Marks (2007, p.73), that nurse educators "need to expand their conceptualization of disability beyond the medical model" holds true if general nursing is to challenge disability inequalities.

There are claims that nursing curricula are guided by the social model in; Australia (Bricher 2000), New Zealand (Seccombe 2007b) and the USA (Smeltzer et al. 2005). However these claims are not all well substantiated. Within the UK there are little more than muted admonitions to take note of the social model (Scullion 2000c, 2001) but as yet no evidence of direct or significant application within general nursing curricula.

Referring to the impact of disability on the individual, Marks (2007, p.71) found that "people's reactions towards them are more difficult to cope with than their disabilities". Nurses were explicitly implicated in demonstrating such negative reactions and Marks (2007, p.70) warns that nurse educators "may perpetuate historical attitudes". This situation is attributed to lack of understanding and knowledge informed by the social model. Marks (2007, p.72) argues that an increase in the number of disabled people as nurses, and other health professionals, "can only improve health care for people with disabilities". While this assertion, with its powerful appeal to logic, acknowledges the effects of contact with disabled people in promoting positive attitudes, it remains an untested assumption.

Carroll (2004) advocates for greater inclusion of disabled people within the US nursing system. The common objection that disabled people would be unsafe, which must not be dismissed

as irrelevant (Sin and Fong, 2008), is countered with the considered response that all students pose a safety risk and that where adjustments are made “nursing students with disabilities pose no greater safety risk than students without disabilities” (Carroll 2004, p.209).

Smeltzer et al. (2005), in a survey of nursing curricula, found that disability simulation, a contested teaching methodology, was still used by around a third of courses. However the major source of information about disability was nursing textbooks. These were scrutinized and found to contain little or nothing on disability. Of more significance is the finding that typical nursing curricula were based largely on medicalised ideas and that models used would not be acceptable nor empowering to disabled individuals. Furthermore this study provides nothing to oppose the view that nursing curricula give inadequate attention to the social model, the potential for nurses to be empowering when dealing with disabled people as patients and inadequate contact exposure to disabled people. They conclude by strongly advocating using the social model to facilitate empowerment and to;

“encourage students to become advocates for the removal of barriers to health care and examine how society and health professionals contribute to discrimination by constructing disability as an abnormal state” (Smeltzer et al. 2005, p.215).

One may draw an ethical distinction between qualified nurses and students being set in the role of change agents, nevertheless most students will qualify and must face such responsibilities.

Desirable as this advocacy role is, this research suggests that nurse educators remain central in challenging disability discrimination and have potential to become vital catalysts in championing improvements.

An interesting case study, again from the USA, provides some analysis following the acceptance on a nursing course of a wheelchair user. While this novel experiment was not without its difficulties it seems that the biggest challenge came from negative stereotypical images associated with disability rather than the adjustments found to be necessary. While very few accommodations were required “it felt as if there was an undercurrent of resistance” (Evans 2005, p.8). In spite of being mistaken for a patient in some settings, the student who was commended for her particular strengths of empathy and advocacy, went on to qualify and gain employment as a nurse (Evans 2005). Where a professionally qualified nurse assumes a primarily supervisory role over other staff that can competently perform technical nursing procedures, the physical abilities of the supervisor will be of limited consequence. This raises the thorny question of ‘task trading’ advocated by Carroll (2004). Task trading describes the sort of informal or formal negotiation within a nursing team whereby the existing skill-mix is matched to the clients’ needs at a given time within a clinical setting. This may be seen as simply an example of using the available strengths, qualifications, background and expertise most efficiently in providing a group of diverse patients with the best possible care. In the case advocated by Carroll (2004), task trading is seen as a creative solution to the situation where the nurse cannot achieve the required technical standards for a given procedure, e.g. urinary catheterization or cardio-pulmonary resuscitation, even after reasonable accommodations and adjustments have been made. Transposed to other settings, this does challenge the notion of the nurse as a knowledgeable doer, with scope for ‘task trading’ being much more limited since very few nurses perform an exclusively supervisory or advisory role.

Collectively these papers hardly represent a celebration of the impact of the social model within nursing, nevertheless in arguing for some acceptance of the social model they add to the growing challenge to the medical model.

Limitations

Before exchanging one model for another it must be acknowledged that the social model has its limitations. One critic has described it as an 'unsociable muddle', with limited agreement over key elements of this paradigm (Light 2000). Others encourage readers to believe that nursing is moving towards the social model, and is "on the cusp of a new era" (Evans 2005, p.18). Indeed Boyles' et al. (2008, p.433) analysis shows that some nurse researchers have identified "an evolutionary shift in the manner in which disability and chronic illness are understood". A paradigm shift, away from the medical model, separating disability from illness, has been shown to be necessary and this paper has articulated calls for such a change within general nursing. It should however be acknowledged that the social model may best be seen as aspirational and sometimes deliberately provocative. Rather than describing current reality it is a useful tool to analyze the situation of disabled people in society and their experience of, and role within, nursing.

Embracing a 'new era' by accepting the social model is by no means a simple or speedy process. Stalker et al. (1999) examined both the declared philosophies and observed practices of non-statutory organizations 'for' or 'of' disabled people. In spite of finding explicit acknowledgment of the social model as their philosophical basis, this study exposed considerable policy-practice

gaps in most of the organizations studied. They concluded that having a “sound theoretical base does not necessarily generate sound practice” (Stalker et al. 1999, p.6). Awareness of the distinction between organizations ‘for’ and ‘of’ disabled people, rejection of the medical model by many disabled people, the requirements in funding bids for explicit user–involvement and the growing amount of legislation promoting the rights of disabled people (Sin and Fong 2008), all provide motivation for organizations to include the social model in their official documentation. However this may simply be a case of “articulation of fashionable ideas without a subsequent shift in underlying attitudes” (Stalker et al. 1999, p.26). Marks (2007, p.17) reports with some optimism that disability discrimination in education, employment and public services has diminished over the past decade but warns that when it comes to health services “the mind-set of medical professionals is more deeply rooted in tradition and has been slower to respond”.

FURTHER IMPLICATIONS

The interplay between subscribing to a model at policy level and changes in attitudes and subsequently in behaviours is complex and slow to manifest in practice. Northway (2000, p.395), who has strenuously promoted the social model and an emancipatory research paradigm, especially within the field of learning disability nursing, admits that it is even “possible to think in one paradigm whilst acting in another”. In arguing for the adoption of the social model one clear danger is a response which is essentially instrumental or cosmetic.

Research exploring the impact of models of disability in general nursing is required. However there is sufficient evidence that the model of disability adopted by nursing is implicated in

contributing to disabled people experiencing discriminatory services. Claims to subscribe to the social model by nurses and health care provider organizations may well be supported by evidence within documented philosophies. Such public affiliations are to be welcomed as a first step in challenging discrimination and promoting disability equality. In practice however and in terms of the dominant images and conceptualizations, the medical model may reign almost unrivalled and continue to influence nursing practice, education and research far more than superficial corporate agreement with the social model. It is clear that the social model is yet to have a significant impact on the collective professional mind-set in general nursing.

CONCLUSION

This paper adds a critical review of the underlying philosophy of some of the ways in which 'disability' is represented in two conceptual models. It attempts to demonstrate links between the medical model and discrimination and argues for a paradigm shift towards a social model of disability. Only a genuine move towards the social model will release some of its potential to challenge discriminatory thinking such that nursing may move from being part of the problem to becoming part of the solution.

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