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The preparation and practice of disabled health care practitioners: exploring the issues.

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Regulatory bodies governing health professions and professional education set clear expectations regarding fitness to practise. Within the United Kingdom the Equality Act, 2010, poses a challenge to regulators, educators and employers to ensure that people are not excluded on the basis of disability and to facilitate inclusion. This research took a mixed methods approach to exploring the tensions between Higher Education providers and placement providers in the health sector. Disabled and non disabled students and health professionals engaged in semi structured interviews and a survey in order to explore their beliefs and experiences. The findings suggest that applying equality legislation within health settings may be particularly difficult and that 'disability' is an ambiguous and multifaceted concept. Whilst small in scale, the findings have given a voice to a professional group who are underrepresented in research and have raised a number of important issues that merit discussion and further scrutiny.

Key words:

Disabled health professionals

Fitness to practise

Professional education

Reasonable adjustments

Word count: 4,795

Introduction

This paper presents the outcomes of research undertaken with health care practitioners from two National Health Service (NHS) Hospitals and health care students, who were registered with the disability services at two English universities, to explore their experiences and preconceptions in relation to disabled health practitioners. The study aimed to make recommendations for the preparation and practice of health professionals, with reference to the Equality Act (Government Equalities Office (GEO) 2010) and the Social Model of Disability.

The United Kingdom (UK), in line with European law, has developed equality legislation. Thus universities when recruiting, teaching and assessing disabled people need to eliminate discrimination and harassment. Prior to the Equality Act (GEO 2010) and Disability Discrimination Act (Department of Work and Pensions 2005) the Special Educational Needs and Disability Act (Department of Education and Skills 2001), led to significant changes in the Higher Education (HE) sector in Britain. This included improved building access and revised policies. Student entitlement is now routine but the focus is on inclusivity within *educational* settings, thus not fully addressing issues of potential impairment relating to disability and fitness or competence to practise in *health* settings.

Health professional education includes a significant period in practice caring for the public under supervision. The majority of placements are provided by the NHS, which is also the largest prospective employer. Many Professional, Statutory and Regulatory Bodies (PSRBs) stipulate the range of areas in which a student must demonstrate competence in order to register and a wide range of experience is generally considered to be an advantage even though once qualified they may choose to work in one specific setting. The

combination of PSRB regulations and placement availability within the NHS and other providers means that flexibility with regard to the range of experience is limited.

On qualifying students are judged to be competent and thus 'fit to practice'. This is defined similarly by all regulators, to include public regard, safety, competence ill health and impairment (for example NMC (2011), AHPRA (2011).

Access to careers in health care is therefore a challenge for disabled people. Work undertaken by Sapey, Turner and Orton (2004) and French (2004) suggests that disabled people continue to face barriers to qualifying as health professionals. There is evidence to suggest that the barriers preventing disabled people from contributing to the nursing profession are deep-rooted and generally accepted (Dearnley, Walker and Fairhall 2010; Sin & Fong 2008). There are also indications that this is likely to be the case in other professions (Murphy 2008, Roberts, Butler and Boursicot 2004). Reviewing standards for teaching, nursing and social work in the UK the Disability Rights Commission (2007) concluded that regulatory standards can be discriminatory thus deterring disabled people from applying for these courses. Research is needed to understand the issues with regard to disability and professional regulation in order to develop shared practice that is safe for the public but not discriminatory.

The Equality Act defines disability as:

> 'A person (P) has a disability if—(a) P has a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities'.

> (GEO 2010, Part 2, Chapter 1, 6.1)

The 'medical model' is defined by Barnes and Mercer (2010) as locating impairments within the individual, thus placing the responsibility on *them* to adapt and fit in with

mainstream society. By contrast the 'social model' holds that the impairment is not of itself disabling, it is the *social* circumstances in which the disabled person must exist (Thomas 2004). Thus wheelchair use is primarily disabling when faced with, for example, a building that is accessed by steps. Campbell and Oliver (1996) point out that the medical model has been pervasive in society; it has had and continues to have a profound impact on the self identity of disabled people.

Much research with disabled HE students has been carried out over the past 10 years (Dearnley & Walker 2009; Dearnley et al 2010; Healey, Bradley, Fuller and Hall 2006; Tinklin, Ridell and Wilson 2004). This has increased awareness of the experience of both disabled and non disabled students and challenged UK universities to develop more inclusive practice. Research with disabled people in professional settings appears to be much less common in general, and very rare within health professions. Grainger (2008) explored the experience of disabled nurses, with a particular emphasis on dismissal due to capability. Crouch (2008) focused on dyslexic students in a health setting. Grainger identifies a pervasive ethos within health care employment that views disabled people as unfit to practice and thus discourages them from attempting to become health professionals whilst encouraging disabled practitioners not to disclose to colleagues. Similar views have been reported in other research (Hargreaves et al 2009). This appears to be a significant aspect of the experience of disabled people that has had very limited scrutiny.

The research reported here was guided by four questions:

1.   What does 'reasonable adjustment' mean in relation to NHS practice placements?

2.   What is the perception of disabled students and staff in the NHS/ other health provision?

3.   How can we help disabled students and prepare them to cope in practice?

4.   How can a balance be found, between the demands of professional health care
       practice and the rights of disabled students and staff?

Methods:

A mixed methods approach was used: the key questions lend themselves to a qualitative approach as they seek to understand the experience of disabled people and perceptions of disability. Such understanding is best explored by asking participants to directly talk about their own experience and beliefs (Streubert and Carpenter, 1999). Additionally, access to health professionals across a number of organisations enabled quantitative data about knowledge, skills and attitudes to be collected.

The target populations were disabled health care students, disabled registered practitioners and non- disabled registered practitioners who were involved in the education of pre –qualifying students within NHS practice placements. Samples were drawn from self selecting students at two universities and practitioners at a number of NHS organisations.

There are methodological difficulties in researching disabled people. This relates, amongst other things, to contested definitions of disability and a perceived reluctance to disclose, particularly amongst professional groups. Thus we acknowledge that the sample we reached should be viewed within this limitation.

Ethical considerations:

These were addressed through the University's ethical panel, the NHS Integrated Research Application System and governance arrangements in each participating hospitals. Informed consent was gained from all participants and confidentiality assured. Access to students was via designated disability officers and to practitioners through approved NHS contacts. The project was monitored by funding partners.

Data collection:

Semi structured interviews were held with disabled students (N = 9), and with disabled, registered practitioners (N = 6). Participants were asked about the experience of being a disabled student or practitioner. A (Bristol On line) questionnaire exploring knowledge, skills and attitudes relating to disability was developed to support the study (N=96). Gaining data on attitudes is problematic; Polit and Hungler(1999) identify a number of what they call 'response set biases'. The 'Social desirability response set bias' is defined as:

> 'the tendency of some people to misrepresent their attitudes or traits by giving answers that are consistent with prevailing social views' (p263)

Attempting to minimise this bias, the design utilised questions from the British Social Attitudes Survey (Park, Curtice, Thomson, Phillips and Johnson 2007), as these have been tested for reliability and validity.

The 15 people interviewed were similar in that they all declared a disability. In contrast the survey reached a wide range of 96 qualified professionals working in the NHS of whom only 20% identified themselves as disabled.

Data Analysis:

Analysis was thematic and iterative. The interviews were transcribed verbatim and Nvivo software was used to create thematic groups from this data and the free text responses to the on line questionnaire. The survey data was analysed to identify descriptive statistics and address the key questions. The research team met periodically through the data gathering phase to discuss and modify coding. Some results of this analysis are presented below.

Results:

Quantitative survey data:

83% were female and 90% White. 50% were nurses or midwives, 37.5% allied health professionals, 8.3% doctors and 4.2% 'others', for example dentistry. Over 80% knew of someone who was disabled, 50% had in the past, or did now, have a role in helping someone who was disabled and 20% identified themselves as disabled. Whilst broadly representative of the NHS no detailed correlation analysis has been attempted at this stage. However the data offers a rare insight into the understanding health professionals have of disability in particular attitudes towards disability, student support and fitness to practise.

Attitudes towards disability:

Over 95% of respondents thought that there was prejudice against disabled people in general. This varied depending on the disability being highest at 96% for schizophrenia and lowest at 61 % for people with dyslexia. Respondents were asked what they believed *people in Britain* thought of disabled people. 83% judged that 'a few/ quite a lot or nearly all' people thought of disabled people as 'getting in the way', similarly 100% with 'discomfort or awkwardness', and 99% as 'needing to be cared for'. When asked if they believed that people in Britain

thought of disabled people as 'the same as everyone else', 66% thought this was the case with 34% saying that hardly anyone would think like this.

Because self reporting of attitudes is difficult to verify, and tends, as Polit and Hungler (1999) suggest, to indicate a socially acceptable rather than personally held view, respondents were next asked the same questions about *their own* beliefs. 12.5% thought of disabled people as 'getting in the way', similarly 21% with 'discomfort or awkwardness', and 80% as 'needing to be cared for'. For 'the same as everyone else', 91% thought this was the case with 9% saying they hardly ever or never thought this.

Whilst there are differences between 'others' and 'self' this may suggests that the health professionals who responded to the survey and are dealing with disabled people on a regular basis share at least some perceived commonly held negative views about disabled people.

A further question asked respondents to say which types of people they would think of as disabled which yielded an interesting response. For example only 64% thought 'someone who used a wheelchair most of the time' was disabled. This led to caution regarding the meaning of responses to questions regarding disability. We theorise that respondents are making distinctions between the impairment that a person might have and the circumstances in which this may be disabling; thus a wheelchair user may be disabled when travelling, but not when reading . This links to medical and social models of disability and the discussion below regarding context.

Student support and fitness to practise:

Supporting disabled students was a source of concern for a number of respondents. 90% said that they had contact with students but only 35% were aware of having had any contact with

disabled students. Whilst 55% stated that for most of the time or always they felt confident in dealing with disabled students for 23% this was only occasionally or never. 68% felt they did not know enough about disability with only 4% saying this was never an issue. 54% felt at least sometimes that they did not know enough about communication needs of disabled students, similarly 56% felt at least sometimes they did not know enough about reasonable adjustments.

Table one includes responses for three questions related to fitness to practise. It indicates a further generalised concern about fitness to practise with regard to students which for some, but not all respondents, was more significant with reference to disabled students. This would suggest that fitness to practise was a concern for many respondents and that disability, albeit important, was only one factor under consideration. The qualitative data below goes some way to exploring these issues.

Qualitative free text responses to the survey and interview data:

Whilst there were some differences between student and practitioner experiences, there was significant overlap and a number of cross cutting themes related to the key questions. These are 'concepts of disability', 'disclosure', 'reasonable adjustments' and 'the patient comes first'. In addition 'enabled not disabled' presents a positive view of disability.

Concepts of disability:

Interviewees talked about their experience of being disabled. Whilst there were positive examples, there was an undercurrent of negativity and lack of self value:

'I think people just see the equipment that comes with you (wheelchair - - white stick) before they see you as a person and what you are capable of. (S3)

' for me its been quite negative in many ways having the sort of diagnosis and just the responses to it' (S2)

Participants identified a number of coping mechanisms. One tactic was simply not to tell people:

'I try not to push it too much, because people get fed up. You know, they've all got their own problems: Away from work, physical, mental, whatever. So I try not to say too much - - - I don't think that ANY of them know that I am registered disabled, cos I've never told them' (R3)

For others coping involved modifying their behaviour or seeking ad hoc help to try to compensate for what they perceived others might find lacking about them:

'so I do everything extra carefully and I am pleasant with people and that helps me you know, the way I conduct my work here' (R2)

'if there's a caretaker at the place, get him to help me, I tend to find I do that, just to get round it. But I do feel a bit of a weak, a weed and a weakling when that happens, so I don't like – that's when I do feel a bit disabled, cos I know I can't do it(R5)

Several participants described disability as an inconvenience to themselves and others. A further example was a participant who only used a disabled parking bay on the days when s/he could not walk from a normal parking spot; it seems that s/he did not consider themselves to be disabled (or disabled enough?) on other days to warrant special treatment. There may be a distinction being made here between the disability, which is permanent, and impairment that is variable or context related.

Disclosure:

Students expressed concern that disclosure would mean that they were treated differently. These fears would appear to have some justifications from the survey data above and from some of the free text comments that accompanied it:

'If undisclosed and errors made puts public at risk'

'Depending on their disability it can be difficult to place them in the workplace'

' Staff reluctant to mentor because it takes too much time and hinders'.(survey respondents)

The interview data from disabled practitioners also explored disclosure. Whilst many were positive, others were selective about whom, if anyone, they told:

'when I get to people who know about mental disability that is when I tend to speak a lot about it. Because I don't give myself the chance to speak to other people because they won't understand'(R2)

'personally I think its important to be open to a degree with colleagues about it, but not like, people you do not know so well'(R5)

For others disclosure was reactive, either to direct questions or pragmatically when the member of staff judged they may not be able to cope:

'I don't (disclose) unless someone asks me to basically. I don't. If I am asked a direct question I will give a direct answer and I won't shy away from it , you know but I wouldn't, wouldn't ever bother saying anything to anyone first through'(R6)

'if I felt it affected me I'd say something, but in the job I am doing at the moment I don't feel it affects me at all'(R3)

We wanted to better understand the important and contentious issue of disclosure. Professional regulators and the NHS understandably wish to know if staff or students are disabled, but legislation supports their right to confidentiality. Health students receive considerable financial support so it is reasonable that NHS sponsors expect safe practitioners but responses to this research seem to support their resistance to disclosure

Reasonable adjustments:

Adjustments that can be made to academic assessment may not be possible in practice. Clinical assessment tasks may be context related such that adjustment significantly changes the assessment criteria. A survey respondent sums this difficulty up well:

'disabled students need to be assessed as being competent to practice in the same way as other students. My concerns are when they are assessed against lesser criteria which may affect their ability to carry out roles once they are qualified, for example reduced caseload management'(survey respondent) .

There were also occasions where participants saw adjustments as not being sufficient or reasonable:

'a key skill for my profession is communication ….We have experienced students with severe numeric and word dyslexia which have made it impossible even with adjustments for them to accurately assimilate information and then keep accurate records'.(Survey respondent)

Here there are specific competencies that cannot practically be compensated for. This data adds understanding to the ambivalence with regard to safeguarding fitness to practise recorded in Table One.

Teasing out an adjustment that is 'reasonable' in a practice context is difficult. Phrases like '*oh she'll be getting special treatment*' (R4) or '*need to be treated as and act as equal team members in workplace*' (survey), illustrate perceptions that reasonable adjustment may allow people to achieve at a lower standard. Disabled students and staff are caught in a dilemma; disclosure and the adjustments that go with it may be needed for the safety of themselves and the public, but may also be seen to reflect negatively on their ability to perform effectively. The students interviewed felt that, rather than being privileged, they had to put in a disproportionate amount of time to keep up to the required standard.

The patient comes first:

Patient care featured in a number of ways: firstly patient care seemed to be used as a benchmark:

'*It is personal ability to undertake a specific role to a high standard which does not require client/service user to be compromised that should be measured*' (survey)

Secondly care may be compromised because disabled staff are either less able or increase others' workload:

'*We need to safeguard our patients as well as staff*'(survey)

'*- you've got to think of the service as well, I suppose. You know, because we've been down this one member of staff ..so other staff have to work harder (R3)*

Finally there is a link to culture, in that participants suggested that staff needs were subordinate to patient needs:

'I know that in the NHS there is a lot of um, it is always said that patients come first, which they do come first, but as well I don't think staff, and sometimes I don't think staff are a priority' (R1)

This represents an emergent theme regarding disabled employees and the role of the NHS and professional regulators that merits further exploration.

Enabled not disabled:

Across the board students and practitioners talked about the skills and qualities that their experience of disability brought to their work.

'even though I'm dyslexic, I have students come up to me that aren't dyslexic, and they're asking me how to do things, how to structure – I'm very good at structuring my work, and putting it into context … 'cos I've had to … learn these mechanisms to cope'(S6)

For patient care, many participants felt their empathy and understanding was heightened by their own experiences:

'I think we're much better at the patient centred stuff, cos we're in it, we're already in that arena' (R5)

Discussion:

A primary function of a university is to provide a high standard of education to its students. Universities, guided by legislation, put a great deal of effort into support to ensure that all students have an equal opportunity to succeed. This research illustrates that it is significantly more difficult to apply the legislation in organisations that are not primarily educational institutions. The NHS is mandated to offer education to health professionals and is at least partially funded to support this, but its primary function isthe needs of the users of its

services. Disabled people who aspire to be health professionals must 'prove' themselves in practice, facing a culture ambivalent about disabled staff and dilemmas about disclosure.

In some contexts assessing fitness to practise is relatively easy: pattern recognition is essential for reading an x-ray and manual dexterity for surgery. In these cases the university can test capability and practice assessors can make judgements about competence. However, it is much harder to assess the point at which a student's ability to record information accurately at speed or to multi-task under pressure falls below a safe level. Despite the guidance offered by PSRBs it is these contextual factors that are difficult to qualify and to manage in practice.

The 'failure to fail' that has been highlighted in nursing by Duffy (2003) suggests that practice educators sometimes do not feel able to fail students. Our data shows that a lack of understanding of and confidence about disability may exacerbate this issue. No one – least of all the disabled people involved – wishes this to be the case. It is thus not surprising that many students and practitioners assume that they alone are responsible for their disability and appear to either actively, or by default, hide it from practice educators and colleagues.

Health professionals need to tease out when there is a genuine threat to patient safety or when it is an excuse not to tackle this difficult and sensitive subject. Disabled participants in our study were very ambivalent about disclosing disability unless they absolutely had to, thus making personal judgements about risk rather than sharing them with colleagues. In some cases they chose to move jobs rather than seek help to remain where they were, thus a valuable and skilled member of staff may be lost. The way an organisation treats its staff is a reflection on its values and strengths. The disabled people involved in this research highlighted many advantages that they brought to their role and a particular sensitivity and

insight into the needs of their patients. This expertise should be celebrated rather than hidden.

Evaluation by Elliot (2010) highlighted that little education and training in equality and diversity is included in qualifying or post qualifying NHS education. This supports the survey findings suggesting that better, accessible, non-judgemental training, dialogue and policies are needed. However, case studies presented in Dearnely et al (2010) concluded that 'disability' is too diverse for any single policy to embrace.

In conclusion, this research has given a small voice to a group of people who are rarely seen or heard. It has highlighted that disabled people can enter health professions and succeed; making a valuable contribution, but that it is often difficult and achieved at personal cost. An open dialogue about the link between competency and fitness to practise is urgently needed to improve the quality of practice education and assessment.

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Tables: Table One: Survey results regarding fitness to practice

	25.f Are you confident about safeguards to ensure fitness to practice?	25.g Are you concerned that reasonable adjustments for disabled students undermine the assessment of fitness to practice.	25.h Are you more concerned about fitness to practice for disabled students than you are for non disabled students.
Always	12.8%	4.4%	3.3%
Most of the time	27.7%	19.8%	13.0%
Sometimes	16.0%	20.9%	20.7%
Occasionally	20.2%	27.5%	23.9%
Never	23.4%	27.5%	39.1%