



Contemporary issues in the training of UK health and social care professionals – Looking after people with a learning disability

Alex McClimens ^{a,*}, Dave Bosworth ^{b,1}, Jacqui Brewster ^{c,2}, Charlotte Nutting ^{d,3}

^a Centre for Health & Social Care Research, Sheffield Hallam University, 32 Collegiate Crescent, Sheffield S102BP, United Kingdom

^b Robert Winston Building, Sheffield Hallam University, Broomhall Rd, Sheffield S10 2BP, United Kingdom

^c 34 Collegiate Crescent, Sheffield Hallam University, Sheffield S102BP, United Kingdom

^d Enable Care and Home Support Ltd, Chesterfield, United Kingdom

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ABSTRACT

The health and social care of people labelled with 'learning disability' has historically been a disputed territory for those individuals working within the nursing and allied health professions. In recent times this situation has seen public debate as instances of poor care and avoidable deaths have received a high profile in the popular and professional presses.

Here we report on a local initiative where students can study for a joint honours award which allows them to practise as a generic social worker and a learning disability nurse. We believe that the inter-professional perspective improves their ability to manage the increasingly complex aspects of health and social care that this client group demands. Furthermore, we suggest that if a similar model were to be applied at a foundation module level to the training of ALL health and social care professionals, then the results would be a win/win situation for all parties. This would also go some way to meeting the recommendations of Sir Jonathan Michael's report, Health Care for All (DH, 2008).⁴

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'...there is a clear need for those who undertake the valuable role and function of supporting people with learning disabilities to have access to relevant education and training'.

[Crickmore and Wray \(2009:292\)](#)

Introduction

As a way of contextualising this paper, it is helpful to provide a brief historical background to facilitate meaning to the arguments presented. Mitchell argues that the health and social care of people with a learning disability fell within the remit of the nursing profession almost by historical accident. He argues further that at various times since its inclusion within the regulations of the General Nursing Council in the 1920s that the branch of nursing which is dedicated to caring for this group of people has not been comfortably situated within what is essentially a clinical care model (2003:350).

The Briggs Report (1972) went as far as to argue that the education and training of professionals who wanted to care for people with learning

disabilities should not form part of the nursing profession. But it was not until the Jay Report (1979) that the likelihood of this being enacted became apparent. However, with a change of government came a change of plan and the idea was mooted that a joint programme of training for those who would deliver this kind of care be devised between the General Nursing Council and the Central Council for the Education and Training of Social Work. No such arrangement was made. Fast forward to the very recent past.

Between 2003 and 2005 and while in NHS or local authority care, six adults, Mark Cannon, Warren Cox, Emma Kemp, Edward Hughes, Martin Ryan and Tom Wakefield, all of whom had a learning disability, died in circumstances which provoked complaints from their families about the treatment and quality of care they had received. The situation prompted a report from Mencap (2007), an independent inquiry (DH, 2008) a government response ('Six Lives' 2009) and the formation of a new regulator, the Care Quality Commission.

In the summary to her report, Ann Abraham, the Parliamentary and Health Service Ombudsman, spoke of 'significant and distressing failures', 'maladministration, service failure and unremedied injustice' and in some cases found that the organisations concerned had 'failed to live up to human rights principles, especially those of dignity and equality' (2009:3). The report did not universally condemn all of the twenty services implicated. None of the complaints made against GPs, for example, was upheld. But in four of the cases the report concludes that the individuals concerned were treated less favourably for reasons related to their learning disability (2009:17).

* Corresponding author. Tel.: +44 114 2255917.

E-mail addresses: A.McClimens@shu.ac.uk (A. McClimens), D.Bosworth@shu.ac.uk (D. Bosworth), J.A.Brewster@shu.ac.uk (J. Brewster).

¹ Tel.: +44 114 2255405.

² Tel.: +44 114 2255692.

³ Tel.: +44 1246599999.

⁴ DH (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities London: The Stationery Office.

The issue we wish to raise here is simply this: people with learning disability routinely receive poorer care and treatment in primary and secondary health care settings than is offered to people without learning disability. Mencap allege that this situation amounts to 'institutional discrimination' (2007:1). We might add this is not strictly a contemporary issue – it is an enduring issue. It is the academic focus which is contemporary. And this situation continues today despite all the warnings, legislation, guidance and policy documents that have been issued. For example, in October 2011, the Parliamentary and Health Service Ombudsman was again in the news with the publication of a report on five complaints about disability issues as they were encountered by individuals in contact with various public sector services (2011). Two of these cases involved people with learning disability being admitted to general hospitals.

Meantime, the Norah Fry Research Centre is currently conducting a confidential enquiry for the Department of Health into the premature deaths of people with learning disabilities. An article based on preliminary findings has found a death rate three times higher than anticipated (Heslop and Marriott, 2011). The full report is due in 2013. These initial findings suggest that it will confirm discrimination, poor care and treatment and difficulties in accessing services continue to prejudice the wellbeing of people with learning disability as they encounter health and social care services.

So the issue is plain enough but what is to be done? In what follows we outline the policy and practice context that informs the debate. We then go on to describe a small pilot study we conducted earlier (McClimens et al., 2012). With reference to this we suggest alterations to the education and training of health care professionals which we believe would benefit them directly by introducing them to a social model of disability. This would improve the care on offer to the population of people with learning disabilities and by extension to other vulnerable patient groups.

Policy and Professional Context

Leeder and Dominello point out that the human population has never been healthier (2005:97). However, in developing their argument, they then detect that health inequality is particularly evident in certain cohorts of the population and here they highlight the situation for people with learning disability (2005:99). Priestley also emphasises the international nature of this phenomenon when he draws attention to the imbalance between the numbers of disabled people and their geographical distribution when compared to the efforts made by respective countries to address their health needs (2001:3). From this it is clear that the health and social care of individuals living with learning disability is of global concern.

Our present paper deals only with one small corner of the world but we believe the implications extend as far as professional care is practised. So while our position is limited by the scope of contemporary UK policy and practice the potential exists to stimulate universal interest. We are here particularly concerned with the ways in which healthcare professionals in training learn about the care needs of adults with learning disability. This is difficult terrain not least because the health needs displayed by this group are significant, being up to two and half times more numerous than those of the general population (DH, 2001). There are implications attached to this bare statistic. McGuigan found that people with learning disability were more likely to die before age 50 than the population at large (McGuigan et al., 1995). In 2010 the public health strategy *Health Lives, Healthy People* confirmed that people with learning disability have significantly shorter life expectancy than their socio-economic status would suggest (DH, 2010). These factors bring them into more frequent contact with primary and secondary care where their more general needs, particularly around communication and compliance with treatment, are often not well understood. It is also well known that this group accesses health services less than they might be expected to given their levels of illness (Emerson

and Baines, 2010). When people from this cohort do attend for treatment or assessment the results, as previously outlined, it can be catastrophic. For when generic health services fail to meet the needs of this population that failure has led to 'discomfort, pain and premature death' (DH, 2010).

There are two strands to this. One is legislative and is outside our remit here and forms part of the anti-discriminatory legislation most recently expressed within *Equality Act (2010)*. The second strand, and this is very pertinent to our concerns, is educational. This is the issue we wish to address. To do this we pose the question, why are so many people with learning disability being treated so poorly in their encounters with health care services? We think that part of the answer must lie within the education and training of healthcare professionals.

And yet there are professional standards which govern the practice of the two biggest groups operating in the NHS – doctors and nurses. Doctors have to adhere to the General Medical Council's *Good Medical Practice (2001)*. Of particular relevance here is para 5 which states:

The investigation and treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age or social or economic status to prejudice the treatment you give.

For nurses advice is given in *The Nursing and Midwifery Council's Code (2008)* which begins:

The people in your care must be able to trust you with their health and wellbeing. To justify that trust, you must:

- make the care of people your first concern, treating them as individuals and respecting their dignity
- work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community
- provide a high standard of practice and care at all times
- be open and honest, act with integrity and uphold the reputation of your profession.

(NMC, 2008:2).

What Is To Be Done?

In the conclusion to their article on reactions of a variety of health care professionals to working with people with learning disability, McConkey and Truesdale note that the descriptor 'people with learning disability' actually applies to a very heterogeneous group. This leads them to be cautious in their claims and they suggest that 'Further research may be needed to explore the reactions of nurses and therapists when dealing with patients with additional complex needs such as multiply handicapped individuals...' (2000: 162).

But the dilemma is not exclusive to the UK. An American study conducted by Sanders et al. (2007) noted that staff they observed are not receiving adequate training in meeting the needs of with individuals identified as having Intellectual or developmental disabilities (ID/DD). The authors state that

'Nursing education programs should strive to address negative stereotypes through inclusion of curricula that specifically target the needs of individuals with ID/DD' (2007:459).'

Two other international studies uncover similar failings. Lunskey et al. (2007) make the point that generic services are simply not designed to cope with the demands placed on them when they have to manage the care of a different patient population.

And in a survey of the quality of healthcare data available on populations with intellectual disability Fujiura et al. (2010) make the point that there is no international agreement on targets for healthcare surveillance for this population.

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