Challenges affecting the learning disability nursing role: past and present

Mark Jukes offers a historical perspective on the changes the specialty has undergone since the early 1970s

Abstract

This article is intentionally reflective, partly autobiographical, and focuses on the challenges that existed for the author as a nursing student trained in the 1970s, and after qualifying as a learning disability nurse. The difficulties of getting changes accepted still exist today. The important messages concern promoting and demonstrating positive values, attitudes and skills when working with clients, other health care professionals and services at all levels.

Keywords

Changes in care, history, learning disability nursing, person-centred care

When giving a presentation at a student learning disabilities nursing conference in July 2009, I shared some of my experiences as a nursing student and on qualifying, and identified some contemporary policy, research and practice challenges facing the profession. A chief motivation behind offering this perspective was a novel by Lucas (2008), which was inspired by that author’s experiences of working as a learning disabilities nurse in a large hospital in Hampshire in the 1970s.

I found it interesting and thought people might like to hear my experiences. In addition, students seem to be increasingly interested in the history and roles of learning disability nurses in what is now a mixed economy of private and public provision.

In the 1970s the challenges faced by learning disabilities nurses in the hospital and in community residential settings often involved trying to get positive change accepted. Today, the issues still centre on promoting change for and with service users in hospital and in the community, and for and with a variety of additional stakeholders, providers and professionals across the landscape of education, health care, social care, leisure and work.

Training

In 1973, I started work in the fifth largest hospital for people with learning disabilities in the UK, and I trained as a nursing student from 1975 to 1978. The experience I gained during this time helped to forge the values and attitudes that would become the bedrock of my practice. During my student years and later, I encountered good role models, and not so good ones too. From these experiences, I developed my personal belief system, acquired positive attitudes to people and discovered how to face and use my, sometimes, raw emotions. This increased my capacity for empathy and advocacy in supporting service users. I also learned how to respect and communicate with people who are vulnerable, and to embrace their values. From that evolved a sense of fairness and dignity in relationships with people.

Some examples of negative experiences included witnessing:

- A nurse flick a person’s ear in an attempt to communicate with them.
- Nurses shouting at people and telling them what to do.
- Nurses belittling clients’ attempts at carrying out a task.
- Nurses using unjustified control techniques.

Such events reinforced my understanding of how not to relate with people. The more positive experiences were found in watching and being involved with...
nurses who would demonstrate fairness, and managing to interact in more individualised ways, such as working and relating with people outside routines, and seeing how this brought out their personalities. Some of the efforts I made to bring about change as a nursing student in the hospital are shown in Box 1. Some staff saw this ‘interference’ from nursing students as an irritating infringement of routine and order.

Abuse witnessed

When I qualified, I handed in my resignation. In my final year I had witnessed the gross ill-treatment of a young man with severe epilepsy by a charge nurse. In those days there was no supervision, mentoring or facilities for reflection. Through the support of like-minded friends we maintained a sense of who we were in spite of the bizarre situations we found ourselves in, often seeking consolation over a few beers in the hospital social club.

In terms of whistleblowing, I reported the charge nurse through the correct channels, but found myself being subjected to harassment from his peers, until I passed my finals and left. I did not receive any support professionally and suffered from burnout (Maslach 2003) and from the effects of a closed institution.

Even back then the hospital appeared archaic, as if stuck in a time warp. As an art college student, I had experienced a liberal, free-spirited atmosphere with contemporary art and music, and a youth culture full of self-expression. It was an era of rapid transition in music and high inflation in the economy. Major industries and manufacturers were reduced to a three-day working week in response to industrial action by coal miners and the need to conserve power. Yet inside the hospital there was post-eugenic segregation, rules, conformity and hierarchical discipline applied to staff and clients, and among staff and clients themselves.

This juxtaposition of the established culture of totalitarian institutions (Goffman 1961) and a new age of sociological enlightenment and social

### Box 1 Efforts made to initiate change in the workplace as a nursing student

- In a children’s home, I organised a small group of children in an unused room to assist them to eat their meals independently. Comments from staff included: ‘What a waste of time’, ‘It takes too long to feed them’, ‘We need to get the meal trays washed and back to the kitchens’. However one senior nursing officer did applaud what I was trying to do.
- In an industrial therapy department in the hospital I initiated art sessions with a small group, supplying my own (leftover) paints and sculpture materials, while the other staff sat in the rest rooms smoking and drinking tea.
- In a home for young men, I developed a ‘How to buy a suit’ programme. By browsing catalogues, measuring each other for fit, and catching the bus to a men’s tailors, patients could purchase a suit for a special occasion.
- On the patients’ annual holiday I took an additional group of five hyperactive children. I was helped by one other like-minded student.
- I joined a small group of staff to put on mini concerts in the evening.
The experience I gained during the 1970s helped to forge the values and attitudes that would become the bedrock of my practice

Policy shifts towards human rights, meant that for nursing students such as myself there was everything to challenge.

Influences

Nigel Evans’s (1981) award-winning documentary, Silent Minority, is an essential resource to help students critically assess learning disability nursing history, because it offers an insight into the harshness of institutional life and what nurses thought about working in such environments. In the film, one student offers a restrained, yet passionate, explanation of why it is important to work with this conflict, since there is little option to do otherwise. To make change happen, the nurse must first do the job ‘as it is’ to be able to make a difference from the outside.

However, students could also work on the system from the inside to promote positive changes – for example, by making small steps towards increasing choice and individuality. Tongue Tied was written by Joey Deacon (1974) who had profound and multiple learning disabilities and whose focus was on 50 years of friendship while living in a hospital. Reading this influenced my perceptions of individual expression and potential capability, and how we should respect each person as being unique. Wolfensberger (1972) published his work on normalisation, but this philosophy was not to have an impact on services in the UK until the 1980s.

After spending six months out of the profession, I applied to work as a staff nurse in a new, purpose-built community residential service. I then became deputy charge nurse in children’s services providing respite and residential care. Maureen Oswin’s work as a social researcher was influential in improving care for children with learning disabilities; her publications such as The Empty Hours (Oswin 1971) and They Keep Going Away (Oswin 1984), revealed the stark conditions in which the children lived and the poverty of the relationships they experienced. Although the service I was working in was better than hospital care, there was still no sense of home or family. As a newly appointed charge nurse, I tried, through various initiatives, to ensure that staff and service users developed their potential as much as possible. The endeavours that did bring results are shown in Box 2.

Subsequently, as the nurse adviser for services for people with learning disabilities in the south west of England, where the politics for change in services were being applied at a strategic level, I became involved in continuing education for learning disability nurses in an interprofessional culture (Box 3).

Today’s challenges

Past difficulties had been largely located in hospital and community residential care, to improve service delivery, change attitudes and support transfer into community re provision. As I developed professionally, I adopted a more strategic level of influence to promote those values interprofessionally, concentrating on the qualities, skills and interventions required to support people individually and positively.

Today of course we have further challenges in terms of the four ‘P’s: primary health care, personalisation, person-centred care and practice. Our specialty also has to deal with the issues of the curriculum, evidence-based practice and what constitutes a skilled workforce in a diverse and mixed-market economy of support services.

Box 2 Initiatives carried out by the author as a qualified nurse

- I confronted sexuality issues with members of staff who thought that consensual relationships between adults with learning disabilities should be non-sexual.
- I helped develop a pioneering community and residential service in the south west of England in which I assessed displaced children so they could be moved to a location nearer their parents.
- I initiated staff training in a rota to suit the needs of the children, not the staff, and used the three-hour handover every Monday for training and educational purposes.
- To aid recruitment I wrote job descriptions to reflect a service based on the principles of ‘normalisation’ and ‘ordinary living’.
- A key worker system was set up for each child, adopting the nursing process, holistic assessments, skills teaching, individual programme planning and effective collaboration between paediatricians, occupational therapists, psychologists, social workers, teachers, parents and families.
- I advised paediatricians on the values, philosophy and skills pertinent to learning disability nursing.
- Following positive audits of the service, I lectured at Bristol Polytechnic for the community learning disability course.
The closure of NHS hospitals and large residential campuses has led to the relocation of people into the community. This has meant that primary health care is now the main service provider for people with a learning disability, rather than secondary and tertiary specialist providers. This requires that they acknowledge and are willing to receive treatment for health concerns.

A number of reports, including Treat Me Right! (Mencap 2005), Death by Indifference (Mencap 2007) and Six Lives (Parliamentary and Health Service Ombudsman 2009), have revealed that the acute and primary healthcare sectors have much to do to improve on the care and treatment of people with health issues and a learning disability. It is here that our field needs to ensure that appropriate education and training of other healthcare professionals are prioritised. This should include development and maintenance of acute-liaison roles and strategic health facilitators to offer leadership and health action planning, and the provision of educational opportunities for generic staff and GP services (Michael 2008).

Recent reforms (Department of Health (DH) 2010) propose that GPs become commissioners. When GPs were fundholders in the 1990s, a survey by the now disbanded community health council revealed that some 40,000 patients with a variety of disabilities and mental health needs were struck off GP registers, and that some patients were deemed ‘too expensive to treat’ (Brindle 1994). Nurses need to be aware of this so that they can ensure it does not happen again.

As far as recent policy shifts are concerned, personalisation is becoming mainstream and is a further issue for learning disability nurses. Since the 1980s, mechanisms for awarding individual service credits (which in contemporary terms, means a form of individual payments awarded to people) have been put forward as a more effective means of providing direct support to people with learning disabilities (Bosanquet 1984).

Now they are becoming a reality, the paternalistic stance of previous governments, which saw block payment contracts awarded to local authorities, social care and healthcare providers, will have to give way to direct or individualised payments that enable individuals to purchase resources, services or support workers and/or assistants to support them, preferably in their own/shared house or tenancy.

The challenge for nurses is the way they present the specialist service they offer. Clear identification and marketing of quality skills and interventions that support the inclusion agenda are necessary if nursing services are going to be purchased. In particular, this involves how community teams and intensive support teams can provide services that focus on health and social concerns, such as mental health, challenging behaviour, safeguarding and abuse, poverty of relationships, isolation in communities and enhancement of personal life skills, so that people can move towards an independent lifestyle.

This may result in nurses supporting individuals with their decision making. For this the Mental Capacity Act (2005) must be applied, because issues such as assessing lack of capacity and best interests may be involved.

Nurses need to understand and apply this legal framework to issues such as:

- The lasting power of attorney.
- Court-appointed deputies.
- The court of protection.
- The office of the public guardian.
- An independent mental capacity advocate.
- Advance directives to refuse treatment.

Nurses can provide advice, links and support which straddle the primary, secondary and tertiary levels of service provision, and they can foster an interprofessional and interdisciplinary approach so that care can be properly co-ordinated.

**The challenge is to think and work in a holistic, person-centred way, and to adopt tools that promote this approach**
Person-centred planning

The government emphasised the use of person-centred planning in Valuing People (DH 2001, 2009). This approach focuses on the person and involves a circle of support. To date, there has been little research into the effectiveness of person-centred planning, but from the information available (Emerson et al 2005), there is evidence that it can add quality to a client’s life and opportunities.

Nurses need to adopt and promote this approach in all assessments, interventions and relationships with individuals, families and other professionals. This means promoting social inclusion and access to mainstream generic services for clients, not only working from a person-centred perspective, but also thinking in a person-centred way. Engaging with the individual about their contribution and priorities from their own perspective is important (see case study panel).

The challenge is to think and work in a holistic, person-centred way, and to adopt tools that promote this approach. The RCN (2011) has published guidance (Box 4) on the contemporary role of learning disability nurses. This document reflects challenging areas highlighted in this article, but the absence of person-centred terminology and perspectives is notable. It is essential that nurses embrace person-centred thinking when following the guidance.

Looking ahead

There are at present 19,000 learning disability nurse registrants recorded with the Nursing and Midwifery Council (Gates 2011a), which means that best value is required from them if quality practice is to be ensured, and that they should work where the maximum benefit is to be achieved. A variety of workforce practitioner focus groups and scoping exercises have taken place (Gates 2011b) which suggest that nurses in the specialty:

■ Specialise in areas such as community nursing, mental health, challenging behaviour, epilepsy, autism and forensics.

■ Base their practice on a ‘sound evidence base regarding the health needs of people with learning disabilities’ (DH 2007):

■ Engage with research – a failure to do so may be seen to threaten the development of professional and academic nursing practice.

It is evident from studies into the research status of the field (Northway et al 2006, Griffiths et al 2007) that most of the work done has been small in scale, not funded and not fit for purpose. The challenges therefore are to raise the status of research in learning disability nursing, gain further expertise in securing funding and be more transparent as a professional.
group working more collaboratively with service users, families and other professionals across sectors.

An intention to move away from traditional local centres of learning disability nurse education towards regional provision is also apparent from the DH (2007). For example, Gates (2011b) has advised that the south central strategic health authority establish a regional academy in learning disability, to provide the regional specialist NHS learning disability workforce. Before strategic health authorities are abolished in 2013, this period of retraction will reveal further proposals on the funding and location of future provision of learning disability nursing, and plans for further commissioned places for students.

Another issue is the impact of the all-graduate admission to the profession and the Universities and Colleges Admissions Service (UCAS) points that students will require to access the field, as opposed to those previously needed for admission to the diploma course.

The main messages to be derived from this personal reflective discourse concern promoting and demonstrating positive values, attitudes and skills when learning disability nurses are working directly with service users and other healthcare professionals or services. A priority is to embed the highest quality person-centred processes in existing primary, secondary and tertiary services, although no service is perfect when attempting to promote person-centred thinking and practice in a mixed-market situation.

Having advocacy on behalf of, and with, people with learning disabilities for respect, dignity and empowerment is fundamental. In primary health care in particular, the aim must be their inclusion in generic services, working within the parameters of the Mental Capacity Act (2005) where a human rights perspective is actively pursued by all.

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References


