Learning disability nursing: a multi-method study of education and practice

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Abstract

This article reports on multi-agency and multi-disciplinary education and practice in the area of learning disability nursing in England. It draws on evidence from a national survey, commissioned by the English National Board for Nursing, Midwifery and Health Visiting (ENB), and an analysis of documents related to the professional education of these nurses, together with observation of their practice. Messages for educationalists, service commissioners, policy makers and learning disability nurses are identified from this study of a professional group that has a long tradition of working with other professionals and in a multi-agency context.

Introduction

In this article, the authors of a English National Board for Nursing, Midwifery and Health Visiting (ENB) Report explore learning disability nursing from three angles. We drew on data collected as part of the ENB study of learning disability nursing in England (Alaszewski et al. 2001), and used this data as a case study of perspectives from education, professional roles and practice. International concerns about the healthcare of people with learning disabilities in the community abound (e.g. Minihan & Dean 1990; Lennox et al. 2001), although in the UK it is widely recognized that community care is generally much superior to that of institutions (Emerson & Hatton 1994). The support of people with learning disability is not only a professional activity for nurses. Practitioners working within learning disability services in the UK operate amidst a variety of agencies: public; not for profit; and private. In the public sector of the National Health Service (NHS), nurses and social workers, in particular, have operated in team settings in the community for many years. Community Mental Handicap Teams, renamed generally as Community Learning Disability Teams, were one of the earliest manifestations of cross-agency, multi-professional working in the UK, particularly in Wales (McGrath & Humphreys 1988). People with learning disabilities and their families are in contact, potentially, with a wide range of public and private bodies, not all of such contacts being with statutory health and social care services but including work, leisure,
relationships and all spheres of ordinary life. UK policy, in respect of people with learning disabilities, increasingly relates to a spectrum of arenas, for example, education, housing and employment (Scottish Executive 2000; Department of Health 2001; National Assembly for Wales Learning Disability Advisory Group 2001). However, these policy moves confirm the importance of better healthcare for people with a learning disability (drawing on research confirming the problems arising from limited physical activity, for example, Emerson et al. 2001), and in England, the White Paper ‘Valuing People’ (Department of Health 2001) proposes individual health plans for people with learning disabilities. While ‘Valuing People’ gives local authorities, not the NHS, responsibility for overall system change and the leadership role, the potential for learning disability nurses to contribute their specialist skills and knowledge is evident. Nurses working in the area of learning disability are expected to facilitate contact with a multiplicity of agencies and promote antidiscriminatory approaches. This article explores their work and its relationship with their educational preparation.

Method

Using evidence from the ENB-commisioned multi-method study (Alaszewski et al. 2001), this article draws on three strands. First, we undertook a survey of 10% of those nurses on the learning disability part of the United Kingdom Central Council for Nursing (UKCC) Professional Register as at March 1999 and living in England. A representative sample of 1864 nurses was sent a questionnaire (response rate 41.9%). The questionnaire explored a range of personal information, educational and employment experiences, and current practice. The majority of questions were open-ended to encourage detailed responses. Respondents remained anonymous. Completed questionnaires were analysed using spss, a statistical package, with responses to the open-ended questions subject to content analysis. Two members of the research team independently categorized this element of the survey responses and agreement was achieved on the categories.

The second element of the research reported here is taken from the same study’s analysis of educational programme documentation, at both pre- and postqualifying levels. A total of 163 programmes’ material, approved by the ENB from 49 higher education institutions, was collected. The analysis covered the programmes’ stated aims and objectives, but also explored their underlying or explicit values, assumptions and methods. It sought evidence of shared learning and of preparation for multi-professional, multi-agency practice. To assist analysis, a grid was developed to identify commonalities and differences. Acknowledging that documentation submitted for approval may not reflect the programmes’ actual delivery, a sample of 12 was chosen for more detailed scrutiny. Nine of these were running relevant programmes at the time of the study, and staff delivering these educational programmes were interviewed, with focus groups with their students held separately. The programmes ranged from pre- to post-registration courses and included joint nurse/social work programmes, specialist nursing practice courses (for example, learning disability and mental health) and diplomas, undergraduate and postgraduate degrees in learning disability nursing.

Moving to professional practice, nurses’ views on their role and the interagency and interprofessional context of their work are drawn from the qualitative responses to the survey referred to above. These are reported below, together with some of the qualitative material arising from interviews of learning disability nurses in practice undertaken through a series of 10 case studies of a variety of agencies. These case studies were undertaken in different settings, different geographical areas within England and different types of practice. More than half of the case studies were located within NHS settings. This division reflected the findings of the questionnaire about the proportions of nurses working in the NHS and in other sectors, but the NHS settings were varied, ranging from a secure forensic unit to a community team. Where appropriate, each of the case studies encompassed interviews with a variety of other practitioners, e.g. healthcare assistants, other nurses, social workers, medical practitioners, and with those in professions allied to medicine,
such as occupational therapists or physiotherapists. Twenty-four learning disability nurses were interviewed and observed in practice. Interviews were then transcribed and, together with the observation records, were analysed through exploration of themes such as knowledge, skills and attitudes. Two-thirds (16 out of 24) of the nurses who were observed in practice completed diaries detailing aspects of their day-to-day practice. Material from this strand of the research is discussed under the headings of role perceptions. Other elements of the research are reported elsewhere, including further details of the methodology, and of user and carer perspectives on the role of learning disability nurses (see Alaszewski et al. 2001; Manthorpe et al. 2003). The research received ethical approval and all personal details and names have been anonymised.

Findings

Employment sector

Most learning disability nurses in England, who responded to this survey, have trained in and continue to work as nurses within the NHS, and an estimated 875 000 patient/learning disability nurse contacts were made in the community in 2000 (Department of Health 2003, Table 1). This is a group that was largely trained in the hospital and residential sector, dominant a decade or so ago. The majority (64.4%) were employed by the NHS, as shown in Table 1, and 518 of the 756 respondents were still working with people with learning disabilities, even though many had trained some years previously.

However, while two-thirds remained in the NHS, only a minority (18.6%) were currently based within hospitals or specialist units in the health service. The majority worked within community-based residential units (51.1%) or provided support to people with learning disabilities, and their families, in the community (28.2%).

The survey also asked nurses to outline the type of activity involved in their typical working week. Questions about activity were open ended to allow respondents to think about their practice without possibly being influenced by what people might think they should be doing. Liaison with other members of the multi-disciplinary team was reported by the majority (79.2%) and liaison with outside agencies by 69.8%. Other prominent activities included administration, especially record keeping and attending meetings, and providing direct support to people with learning disabilities and their families. However, only 28.4% of those responding felt that team working was a skill required for their current work. This was rated as secondary to skills in general management (identified by 56.6%) and communication skills with people with learning disabilities and their families (46.9%). Furthermore, only a minority (7.6%) felt that knowledge was required for liaison activities, and very few (2.2%) felt that it was important to have attitudes and personal skills to work independently or in a team.

Educational preparation

In order to explore further the knowledge base and skills required by learning disability nurses, the research analysed educational documentation. This provides an overview both of what educationalists perceive as relevant to practice and lifelong learning and, because such documentation was subject to approval by the ENB (and in some cases the professional social work accreditation body), it provides evidence of what the profession, employers and other stakeholders consider makes students 'fit for practice'.

The educational curricula varied. Pre-qualifying programmes aimed to prepare students to become professionally registered nurses, and students on

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Table 1 Current employment by sector of learning disability nurses, by percentage (n = 587)

<table>
<thead>
<tr>
<th>Sector</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>NHS</td>
<td>64.6%</td>
</tr>
<tr>
<td>Private organization/self employed</td>
<td>16%</td>
</tr>
<tr>
<td>Local authority social services</td>
<td>10.5%</td>
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<tr>
<td>(local government)</td>
<td></td>
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<tr>
<td>Voluntary/not for profit</td>
<td>6.5%</td>
</tr>
<tr>
<td>Education</td>
<td>1.8%</td>
</tr>
<tr>
<td>Joint local authority/NHS</td>
<td>0.8%</td>
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the learning disability branch shared an initial common foundation programme with nurses on other ‘branches’. Such programmes aimed to provide all-round competence as nurses and thus their documentation was often general. A number referred to enabling students to develop into ‘confident’ or ‘flexible’ nurses in general terms in the area of learning disability nursing. Some were more sophisticated and their aims included reference to other professionals and systems of care outside health services. For example, a pre-registration degree programme aimed to produce:

… a competent, flexible, caring practitioner, teacher and manager who is able to function autonomously and in partnership with other healthcare professionals, formal and informal carers and clients in the hospital and the community.

Postqualifying programmes were more specialized and their aims were more focused. They aimed to provide specialist knowledge in relation to specific areas; however, some referred to the potential for such specialisms to be related to the work of other practitioners. For example, a postqualifying module on ‘epilepsy’ included the following aim for students:

To identify progressive aspects of care within nursing, or multi-disciplinary approaches to caring for people with epilepsy.

However, a more detailed content analysis of the programmes’ coverage of areas of knowledge, skills and values revealed that systems of care and multi-agency support and the role of the multi-disciplinary team were taught in a majority of pre-qualifying programmes (eight out of 11). Virtually all covered other areas, such as the influence of social, political and cultural factors on individual care and social policies relating to people with learning disabilities. All pre-registration programmes indicated that working as part of a multi-disciplinary team was a core skill for students. This is not surprising, because the Code of Professional Conduct for Nursing makes this a specific requirement (Nursing and Midwifery Council 2002). Eight out of the 11 also reported that multi-agency working was included in their curricula.

In interviews, the lecturers delivering the curriculum also referred to knowledge and skills in multi-agency work as necessary elements for their graduates. Not surprisingly, those working on joint nurse/social work qualifying programmes stressed the importance of a broad ability for work in a range of environments that this type of course aimed to instil:

It equips practitioners to work across all fields and with the partnerships and action documents in the current Health Bill … then these people will be the practitioners for the future.

However, a lecturer working on a more traditional learning disability diploma pre-registration programme indicated similar aspirations:

We try to produce, at the end of it, a balanced practitioner who has a wide range of skills and who is able to work in a wide variety of settings.

At both pre- and postqualifying levels, lecturers made reference to the influence of potential employers on their students. The NHS was predominant in being involved in course design through formal links and also through its staff’s involvement in teaching or in the provision of placements. However, some private companies were developing links with Higher Education institutions; in one example, a company that specialized in high-level support services had developed a close relationship with a postregistration programme. The educators saw this as being mutually informative.

Role perceptions
This section reports on nurses’ perceptions of their world of work. It draws on open-ended questions
from respondents currently working in learning disability services \((n = 518)\). Many of these respondents had worked during the time of major changes in policy and service provision, particularly the closure of nearly all long-stay hospitals in England. Almost 30\% had qualified before 1980 and had thus witnessed the move from NHS hospital provision to ‘care in the community’. For most this was welcome; one nurse commented on the shift in her work:

> My job is now about making people feel valued – not about nursing or looking after people with learning disabilities.

Nonetheless, while embracing the move from hospitals (or custodial care, as some perceived it) to care in the community, nurses were critical of certain aspects. In particular, some voiced their apprehension at the effects of a market for care. This was regretted in its manifestations within the NHS internal market and in the ‘business’ of care. Several respondents associated this with an unwelcome increase in their administrative tasks, particularly ‘paperwork’. Other implications included broader and more diverse responsibilities over matters that might formerly have been undertaken by hospital administrators, such as budgeting and day-to-day facilities management. In contrast, other nurses reported that they had developed a more focused role, working within particular clinical specialities such as epilepsy, challenging behaviour or forensic services. Some had experienced a dilemma in choosing between client care and managerial roles; the latter being reported as the sole route to career progression.

Learning disability nurses perceived their roles as focused on client care; however, when interviewed, a number made reference to their roles in managing unqualified social care staff, in residential units, for example, and in advising other professionals. These elements were combined, for the nurses maintained that they were often the only members of a unit or team who had received specialist learning disability training. One nurse described her role in the community:

> Your average GP finds it very difficult to establish what’s wrong – unless it’s very obvious – if there’s a lack of communication, so it’s down to our observation to be able to give the doctors pointers to what might be wrong.

While other professionals had specialist knowledge, such as in medical or employment areas, learning disability nurses often emphasized their overall and integrated knowledge and skills. Nurses saw this holistic perspective as a major justification for their role. One argued that learning disability nursing provided:

> … a method of working through and considering all areas and then drawing that back together.

For some, this ability to take on many roles was the defining element. One nurse considered:

> I think (learning disabilities nurses) have a multiplicity of roles that go between professional carer to advocates, sometimes a surrogate parent, and often with that it differs from other forms of caring in that we have to harmonize our jobs together, and treat clients holistically.

However, other nurses appeared conscious that their role was undefined and potentially unfocused. Some reported that they had found it necessary to achieve some clarity over their skills, particularly when working with other professionals. One nurse working in a multi-disciplinary team outlined its operation thus:

> Because of the MDT [multi-disciplinary team] meetings we are aware of each other’s skills and we just call on each other as professionals, as and when needed … (We) look to each other for what skills we’ve got. So if I want something like an adaptation I know to go to the OTs [Occupational Therapists] and if they want something that’s ‘nursie’ they come here.
This nurse cited taking blood pressure as a ‘nursie’ skill; others’ examples included assisting with medication, giving advice about challenging behaviour and offering therapeutic support.

In contrast, other nurses outlined numerous areas where members of the multi-disciplinary team had interchangeable skills, such as assessing need. Interviews with their colleagues also accepted this overlap. Specific examples included support for mental health problems, behaviour techniques, and support and education around personal and sexual relationships. Both nurses and social workers were seen as equally able to coordinate care plans. Both nurses and unqualified staff were reported as able to help people with personal care and with activities of daily living. Those with a health service background or social work qualifications appeared to see nurses as having clinical skills and deferred to their knowledge around medication, health needs assessment and their ability to negotiate health services. One occupational therapist, for example, reported her experience of working with learning disability nurses in a multi-disciplinary team:

… the nurses in this team are looking at any health issues – advice on GP visits, overlooking medication, monitoring side-effects of medication, going along to GP and consultant visits – anything to do with health implications.

Discussion

There are some limitations to this study, including the response rate to the questionnaire being only 41%, and thus conclusions drawn need to be treated with some caution as they may not be fully representative. With hindsight, the length of the questionnaire may have contributed to this, but those who did respond have provided a wealth of detail about themselves and their practice. The educational material we analysed may have represented aspirations rather than reality, and the sample of educational institutions in which we conducted interviews may have been atypical. Similarly, we may have observed practice in atypical teams and thus may have observed or interviewed nurses and other professionals who had a positive commitment to teamwork. However, the data we collected resonated with others’ findings (Norman et al. 1996; Boarder 2002; Mobbs et al. 2002) and we therefore have some confidence in the findings.

The data reported above relate to a profession that has moved from monolithic education and service provision, in long-stay hospitals, to work within a broad range of locations and agencies. Learning disability nurses’ practice, encompasses a span of tasks. It is a profession which is involved in multiple roles and various educational opportunities. It is not simply that service users have moved from hospitals to ‘the community’, but those providing education and support to practitioners have also done so. The world of community care for people with learning disabilities, and nurses working with them, takes place in a diverse and changing range of settings. Even the NHS, while still the main source of employment, is composed of a multiplicity of teams and units, as the case studies illustrated. This immense variety is confirmed by other studies, such as the survey undertaken by Mobbs et al. (2002). In their survey of learning disability nurses in NHS teams, activity ranged from specialist practice to general support and was carried out within teams composed of a range of professionals (Mobbs et al. 2002, p. 14, Table 1).

What can we learn from this workforce that spans health and social care and has knowledge of and skills in working in arenas where teams of a variety of form and multi-agency practice are common? There are four main audiences to whom the findings may be relevant:

1. Educationalists.
2. Commissioners of services.
4. Learning disability nurses.

Educationalists

For educationalists, one key, possibly comforting, message is that their programmes reflect, in theory and in delivery, the multi-agency world of service delivery. As Norman et al. (1996) noted, learning disability nurses are evidently being prepared for a complex service world and their education aims
to equip them to understand how systems have evolved and continue to change. However, currently, stakeholders in programme delivery and some of higher education's strongest partners appear to be senior managers from the NHS. The NHS is, after all, paying for the majority of training and is the main source of employment. New relationships may need to emerge with the advent of Training Organizations in the Personal Social Services, Skills Councils and other groupings, especially the independent sector. These need to encompass all employers. In education, as in services, there may need to be delicate balancing of competitive interests.

In this research, we identified possible tensions emerging between providers of services (who prioritize managerial and practical skills) and nurses (who value education as a means to enhance their direct care work with service users and their families). The nurses’ views in this study appear to reflect those of their colleagues and professional leads (Beacock 2001).

Evidence of shared learning with other professionals and interprofessional education was limited in this survey, although the existence of a minority of joint nurse/social work pre-qualifying programmes clearly represents ‘hybrid’ or integrated professional training. With these exceptions, we found little evidence of shared learning; this seemed not so much the result of professional insecurity, as suggested by Elston & Holloway (2001), but more connected with ‘mundane’ matters, such as practical and logistical difficulties (Freeth 2001). Such problems may be particularly associated with the small numbers of students (and thus staff) on the learning disability branch of nurse training and this may mean that they are not obvious partners for other (larger) professional training programmes. One message for educationalists is that they may need to think further around issues of shared learning and interprofessional experience, and exchange ideas of good practice and what works, or practice outcomes.

Commissioners of services

For commissioners of services, trained learning disability nurses represent sources of expertise and are a key means to the delivery of the agenda set by central government in England under its ‘Valuing People’ initiative (Department of Health 2001). This steers learning disability nurses and other related personnel to enhance access to health services for people with learning disabilities, perhaps as ‘health facilitators’. It is suggested, in such policy initiatives, that nurses should focus on key events for people with learning disabilities, including transfers from children’s to adult services and possible moves associated with the ageing or death of parents. These roles fit comfortably with the professional education we explored and they play to learning disability nurses’ holistic skills, their desire to forge and sustain relationships with users and carers, and to provide both with appropriate support over difficulties such as behavioural distress. In this way, commissioners of services, such as NHS Primary Care Trusts, may see learning disability nurses as an experienced, confident and competent workforce, being familiar to the primary care team and relevant social care staff locally, if not to the structures of the new Trusts (Bollard & Jukes 1999). Powrie’s (2003) study of practice nurses in an area of Scotland recently identified such nurses’ need for closer support from their local learning disability colleagues. However, evidence from this research suggests that learning disability nurses also have the potential to support, educate and manage social care staff. Commissioners may wish to see them not simply as practitioners involved in one-to-one client or family support, but as resources for the broader (even integrated) primary care team and social care colleagues. There is evidence from this research that many nurses have skills in supporting and managing other practitioners – most notably when working in the residential sector – making use of their skills in management, quality assurance and business planning.

Health and social care policy makers

Health and social care policy makers have emphasized the needs for increased flexibility, the promotion and funding of shared learning, and the incorporation of staff who do not come from traditional professional training backgrounds. The
British government has invested in a variety of policy initiatives requiring staff to span traditional boundaries; these initiatives include the Connexions service for young people leaving school, and mental health support workers and staff working in area-based initiatives such as child care (for example, in Sure Start programmes). Learning disability nurses may face new demands on their expertise from such workers, all of whom may be seeking to develop work with people with learning disabilities, who may have little contact with health or social care services. Such a role suggests a range of potential roles for learning disability nurses beyond the usual health ‘family’ into the worlds of employment, adult learning and community development. Their role as advisory professionals, supporting the supporters, may entail less contact with individual clients and their families. Policy makers may wish to evaluate the benefits of employing learning disability nurses in such roles, compared, say, to specialist psychologists, social workers or the social pedagogs, more commonly found in Europe working within the whole domain of children's education in its broadest sense (Moss & Petrie 2002).

Behind such detail lies the long-established debate over the proper balance between specialists and generalists in social care and healthcare (Norman 1998; Horwath & Shardlow 2003). As we observed, learning disability nurses have been able, through different educational routes, to operate within a highly variable service context, and to develop into and act as specialists, or to maintain a general role. As policy makers may recognize, this has equipped such nurses to respond to the ‘discovery’ that people with a learning disability may benefit from assistance in accessing health services (NHS Executive 1998). Their subspecialisms appear particularly responsive to local priorities and service demands, and this research confirms the findings of Mobbs et al. (2002), that specialists in challenging behaviour, child health and epilepsy are the service priorities. However, the survey (see Table 1) confirmed that learning disability nurses do not just work across primary care and social care. They are also able to link primary and specialist services, whether in the area of meeting general health needs or by involving specialists from secondary or tertiary care. This research noted nurses’ possible links with in-patient psychiatric services, for example; others have explored how they may work collaboratively with both primary and specialist staff to facilitate medication reviews, information sharing and care planning (Cassidy et al. 2002).

Learning disability nurses

Finally, this research has messages for learning disability nurses at this time of change. It has identified that the broad nature of its professional training makes for a workforce that is flexible and able to negotiate roles within a multiplicity of teams and agencies. It is a health profession that is unique in the breadth of its employment base, located among the various sectors, and spans community support to secure or forensic hospital services. It works across the life course and with both service users and their families. There are few professionals who have such a range of activity, which includes direct client work as well as service management and strategic developments. It might seem that this should be a self-confident profession, and some commentators have observed that, contrary to the professional pessimism of the 1990s, the role of learning disability nurses is ‘surely secure’ (Mobbs et al. 2002, p. 18). However, the survey and interviews with practitioners revealed continued anxiety about the long-term future of learning disability nursing and this may be connected to the wider fears for the future of social care as it becomes more closely linked to, or even absorbed by, health interests (Hudson & Henwood 2002) that focus on ‘cure’. Much will depend on evidence of outcomes from the skills, knowledge and competence of learning disability nurses and this might be usefully part of any analysis of the impact of new policies.

Conclusions

Learning disability nursing has moved from a narrowly defined role, within long-term care, to a broader role within the NHS and beyond. Educational preparation reflects the multiple activities of the learning disability nurse. However, in practice,
many nurses appear not to consider that skills are needed for multi-disciplinary and team working and take a narrow view that they will function more effectively if they are better managers. A minority see working with other professionals as requiring knowledge on their part, and very few consider that personal attributes or attitudes are salient to their knowledge on their part, and very few consider that working with other professionals as requiring effectively if they are better managers. A minority and take a narrow view that they will function more needed for multi-disciplinary and team working. Many nurses appear not to consider that skills are needed for multi-disciplinary and team working and take a narrow view that they will function more effectively if they are better managers. A minority see working with other professionals as requiring knowledge on their part, and very few consider that personal attributes or attitudes are salient to their knowledge on their part, and very few consider that working with other professionals as requiring effectively if they are better managers. A minority and take a narrow view that they will function more needed for multi-disciplinary and team working.

References


