

# Learning from the past – setting out the future:

**Developing learning disability nursing in the United Kingdom**

An RCN position statement on the role of the learning disability nurse



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The Royal College of Nursing (RCN) is the largest professional association for nursing in the UK. With over 400,000 members the RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

To deliver our mission we aim to:

- represent the interests of nurses and nursing and strengthen their voice locally, nationally and internationally
- develop nurses' professional practice through education, building a resource of professional expertise and leadership
- influence and lobby government and other stakeholders to develop and implement policy that improves the quality of patient care, and builds on the important contribution of nurses, health care assistants and nursing students to health outcomes
- develop the science and art of nursing and its professional practice
- build a sustainable member-led organisation with the capacity to deliver our mission and strategic objectives effectively, efficiently and in accordance with our values
- support and protect the value of nurses and nursing staff in all their diversity and in all employment sectors.

The RCN makes the following pledge to people with learning disabilities:

- the RCN will, through its membership, seek to ensure that safe, human rights based practice is the top priority for nurses
- the RCN is committed to working with individuals, services and stakeholders to ensure the necessary safeguards are in place across all practice settings that enable safe practice and care
- the RCN recognises that vulnerability is a particular issue and concern for people with learning disabilities and in this regard will, through the RCN Learning Disability Nursing Forum committee, seek to highlight issues and raise awareness of the needs of this group within society
- the RCN will promote equality, diversity and the rights of people with learning disabilities, and person-centred approaches to care
- the RCN is committed to working in partnership with people with learning disabilities and their families and carers, to ensure needs are identified and effectively met
- the RCN will inform, shape and influence learning disability policy in England, Scotland, Northern Ireland and Wales to improve the care and support of people with learning disabilities
- the RCN will support and develop learning disability nurses to provide high quality nursing care, support their nursing practice development, and enable them to act as leaders and professional role models.

# Introduction

The population of children, adults and older people with learning disabilities is increasing and changing. Thanks to better neonatal care and improvements in health and social care services people with learning disabilities are living longer and into older age.

As a result of improved pre-term neonatal survival rates, the diagnosis of rare syndromes and growing substance abuse among the population, the incidence of children and adults with learning disabilities is increasing. Similarly, the incidence of Foetal Alcohol Spectrum Disorder (FASD), Attention Deficit Hyperactive Disorder (ADHD) and Autism Spectrum Disorder (ASD) is also higher. This trend is being compounded by wider issues such as social disadvantage and poverty (Emerson and Hatton, 2007; Blackburn et al., 2010; McKay et al., 2010).

As a result there is a new and growing population of children and young people living into adulthood with a range of complex needs (Tyler et al., 2007). Collectively these issues are resulting in cohorts of children and young people presenting with patterns of complex learning disability unlike those previously experienced by existing services. In the last five years this group has increased by 25 per cent and is anticipated to increase a further 29 per cent in the next five years.

In addition, a growing number of adults with learning disabilities and associated health needs are living into older age (Torr and Davis, 2007).

As a consequence, the population of people with learning disabilities is increasing at both ends of the age-continuum and all care services – whatever their focus – will experience more demand from this group in the future (Emerson and Hatton, 2008; Parrot et al., 2008).

## Examining the need

A growing research evidence base illustrates the high and unmet health needs experienced by children, adults and older people with learning disabilities and the resultant impact on their health care experience, quality of life and mortality.

Compared to the general population, people with learning disabilities experience a different pattern and higher frequency of health disorders (Cooper et al., 2004) that include a high prevalence of respiratory disease, as well as cardiovascular, gastric, neurological, haematological, musculoskeletal disorders, sensory impairments, and mental illness (NHS Health Scotland, 2004; Jansen et al., 2005; Disability Rights Commission, 2006).

As a result it is common for people with learning disabilities to present with multiple, layered, physical and mental health needs. When coupled with issues relating to communication, behavioural challenges, autism spectrum disorders, mental illness and early onset dementia, this group experiences particular vulnerabilities when accessing and receiving health care (NHS Health Scotland, 2004; Kwok and Cheung, 2007). These needs create significant challenges not only for people with learning disabilities, but for their families and service providers too.

Recent investigations and inquiries have identified significant service and system failures in both specialist health and general health services which have contributed to poor care and support for people with learning disabilities (Mencap, 2004; Healthcare Commission, 2006; Healthcare Commission, 2007; Mencap, 2007; Parliamentary and Health Services Ombudsman, 2009).

These investigations and inquiries all highlighted the need for education and development to ensure that health care practitioners are aware of the needs of people with learning disabilities, and have the knowledge and skills, or can gain access to specialists who do, to provide person-centred care that is appropriate to the needs of the individual and their family.

# Learning disability nursing in the UK

“Nursing is the use of clinical judgement in the provision of care to enable people to improve, maintain or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.” (Royal College of Nursing, 2007)

The five defining characteristics as set out in the RCN *Defining nursing* publication (publication code 001 983, [www.rcn.org/uk/publications](http://www.rcn.org/uk/publications)) continue to be relevant in learning disabilities nursing today.

There have been significant changes and developments in services for people with learning disabilities over the past twenty years. Today people with learning disabilities live in the community and are supported to lead full and inclusive lives, with the full recognition that access to specialists with knowledge, skills and experience of their range of health needs will be necessary for some.

Recognising the need for specialist support for people with learning disabilities, the RCN supports the emergence of learning disability nurses and their important role in delivering patient-centred care (Royal College of Nursing, 2007).

Learning disability nurses (LDNs) play a central role in the lives of people with learning disabilities, particularly those with more complex care needs. They do this in a range of ways, including:

- undertaking comprehensive assessments of health and social care needs
- developing and implementing plans and programmes of care
- working in collaboration with other professionals and disciplines to meet health needs and coordinate care
- providing nursing care and interventions to maintain and improve health and promote wellbeing
- enabling equality of access and outcomes within health and social care services
- providing advice, education and support to people with learning disabilities and their carers throughout their care journeys

- providing education and support to promote healthy lifestyles and choices
- providing education and development opportunities for other practitioners on the needs of people with learning disabilities
- acting to safeguard and protect the rights of people with learning disabilities when they are vulnerable and in need of additional support.

# The RCN Learning Disability Nursing Forum

The Royal College of Nursing is organised into 41 professional nursing forums, each of which is structured to give members the opportunity to develop, contribute to, and lead cutting edge nursing practice that improves the delivery of care in a particular nursing speciality or area of interest.

The RCN Learning Disability Nursing Forum is led by an expert committee, and is focused on developing and improving nursing practice to enable nurses to address more effectively the health needs of people with learning disabilities. The committee, which is comprised of seven members, coordinates a shared agenda in health and social care settings across all four UK countries.

To deliver this agenda the RCN Learning Disability Nursing Forum committee works in partnership with other key stakeholders involved in improving and shaping learning disability nursing practice.

For example, the RCN has worked with the UK Learning Disability Consultant Nurse Network, the Positive Choices Learning Disability Student Nurse Network, and the National Network of Learning Disability Nurses (NNLDN). These collaborations have brought about enhanced communication and proactive engagement and participation from all four UK countries.

Through its membership the RCN is aware of the issues and concerns experienced by learning disability nurses (LDNs) and health care support workers across a variety of care settings. In 2010, members attending RCN Congress called for learning disability liaison nurses to be employed in all general hospitals to help address the problems of poor care experienced by some people with learning disabilities. This resolution has attracted significant media and public attention.

To take this resolution forward, and to scope the future support needs of children, adults and older people with learning disabilities, the RCN Learning Disability Forum recently co-hosted a UK-wide summit, inviting experts and stakeholders to identify the key issues and actions required now and in the future.

# The 2010 Learning Disability Nursing Summit

In June 2010, Dr Michael Brown, Chair of the RCN Learning Disability Forum committee and Phil Boulter, Chair of the UK Learning Disability Nurse Consultant Network co-hosted the Learning Disability Nursing Summit in London.

The summit involved invited experts alongside senior learning disability nursing leads, policy makers, researchers and educators. The focus of the day was around three key strategic elements:

- education
- workforce
- leadership.

Issues relating to each of these key areas were discussed and debated, and key actions and priorities for the RCN were identified and agreed.

This position paper contains a summary of the key issues identified and discussed at this summit.

## Education

There is a growing need for nurses in the field of learning disability. This requirement needs to be set within the wider context of the care such nurses provide, enabling health needs to be effectively addressed across settings, bringing about improved health outcomes and enabling social inclusion. The Nursing and Midwifery Council (NMC) standards for pre registration nursing programmes, issued in 2010, provide the basis for the development and delivery of contemporary education programmes to prepare the learning disability nurse of the future (Barr, 2009).

Nurses at both pre and post registration levels must be educated to make decisions about nursing care and support needs if they are to effectively contribute to current and future service delivery across a range of care settings – hospital and community based, as well as those outside of specialist learning disability services.

As services and the evidence base relating to the health inequalities and the interventions required by people with learning disabilities evolve, nurses will need to keep their knowledge and skills up to date through reflective practice and a

commitment to personal learning. In addition, to be safe and effective practitioners, nurses will need to undertake ongoing accredited education to ensure their skills remain ‘fit for purpose’ (Nursing and Midwifery Council, 2008).

There will also need to be opportunities for nurses to build further on the knowledge and skills obtained within pre registration nurse education in order to develop areas of specialist practice, characterised by ‘discretion in clinical judgement’ and with a continued emphasis on nursing knowledge, theory and skills (UKCC, 2001).

Integral to the role of LDNs will be a wide range of practical clinical nursing skills necessary to assess and respond to the diverse range of complex health needs experienced by people with learning disabilities, and to deliver a person-centred approach to care and support.

As the academic level of nurse education develops to degree level for all pre registration nursing courses (with the consequent move to a post graduate level of post registration courses) the need for a continued commitment to practice-based learning must be continued and developed. The design, delivery and evaluation of pre and post registration nursing learning opportunities will require the active collaboration of practitioners across all relevant professions in all practice settings, as well as people with learning disabilities, their families and carers, and educators in higher education.

Education for nurses must recognise the inter-professional context within which LDNs provide services. There is a need and an opportunity to provide shared learning across professions at pre and post registration level in higher education and practice settings, and for students and practitioners to undertake their professional education and continue to meet the requirements of their respective professional and regulatory bodies.

### Key issues

- Ensuring the on-going ‘fitness for purpose’ of the learning disability nursing workforce for the future.

- education and practice.
- Structuring pre and post registration education programmes on the evidence of health needs now and in the future.
- Setting out the distinct contribution of registered LDNs and health care support workers to improving health and wellbeing for people with learning disabilities now and in the future.

#### The ways forward

- National and local action to develop and enhance practice-based learning opportunities that support evidence-based nursing practice.
- National and local action to develop and enhance post registration learning opportunities for LDNs and health care support workers which reflect the changing and evolving roles required to meet the needs of people with more complex care needs in the future.
- Build on the NMC's pre-registration proficiencies to develop evidence-based curricula for the future.

## Workforce

Learning disability nurses currently practice in a wide and diverse range of organisational settings that include the NHS, local authorities and the third sector, and it is clear that they will face new challenges to their future roles (Alaszewski et al., 2001).

The changing demographics of children, adults and older people with learning disabilities means the learning disability nursing workforce of the future will work with growing numbers of people with a range of complex health needs.

Central to this challenge will be the unprecedented changes that take place in the configuration of services and support for people with learning disabilities and their families. These changes will dictate a range of new roles for learning disability nurses across the UK, for example, supporting and facilitating health care in general hospitals, providing psychosocial

interventions for those with mental illness, and working with colleagues in primary care to enable health screening.

In the future LDNs will practice within child and adolescent mental health teams with greater frequency and support people with learning disabilities in behavioural distress. Other developments will see LDNs take on other roles, becoming custody nurse practitioners or practitioners within forensic services.

Community learning disability nurses are already developing new and specialist areas of practice such as sexual health, epilepsy, challenging behaviour, early onset dementia, and end of life care, while maintaining a core learning disability background to their practice (Gates, 2009).

To ensure there are adequate learning disability nurses to meet future needs, strategic workforce planning must take account of future needs across the NHS, social care, and third sectors. However, currently workforce planning is typified by an uncoordinated reduction in the number of universities providing the learning disability nursing programme across the UK, and limited and uninformed workforce development and commissioning in the context of a burgeoning learning disabilities population.

To deliver the evolving personalisation agenda there will be a growing need for a specialist learning disability NHS workforce, and the largest single component of this workforce will be LDNs (Gates, 2009).

The future specialist workforce needs to be strategically commissioned, and this is best achieved through stronger and more transparent alliances between those charged with commissioning learning disability nurse education programmes on behalf of the NHS (Gates, 2010). In particular, the NHS needs to acknowledge and fulfil its statutory responsibility to undertake planning that takes account of the workforce needs of the third sector, and to ensure that the wider NHS workforce is properly prepared to meet the needs of people with learning disabilities and their families (Barr and Gates, 2008).



## Key issues

- Education commissioning needs to support a flexible practice learning that is reflective of local workforce requirements.
- The effective evidence-based commissioning of pre and post registration learning disability nurse education across the four countries of the UK.
- Effective workforce modeling across health, social care and third sectors is needed to identify future registered nurse learning disability (RNLD) requirements now and in the future.

## The ways forward

- Partnership working with the health departments of the four countries of the UK to illustrate the role and contribution of learning disability nursing to improving health and wellbeing, which in turn enables the social inclusion of people with learning disabilities.
- National work needs to be undertaken by each UK country as a matter of priority to profile the existing learning disability nursing workforce and identify future requirements.
- Effective workforce planning partnerships – involving the NHS, social care and third sector providers – need to be established with planners, commissioners and educators to ensure an effective learning disability nursing workforce.
- The range of future employment opportunities for learning disability nurses, in the context of increasingly complex care needs, need to be set out and mapped.

## Leadership

Learning disability nursing needs effective leaders to influence and inspire practitioners and ensure their knowledge and skills are maximised, and inform others of the professional and education needs of this part of the workforce (Faugier, 2005; Department of Health, 2006).

However, the changing pattern of service delivery has led to a lack of focus on the need for effective leadership to ensure the professional

development needs of LDNs are identified and met wherever they practice – be it in the health service, social care or third sector settings. As a result, networks are playing an increasingly important role in enabling LDNs to develop, communicate, and share nursing practice. Leadership is required to ensure these networks function effectively and successfully (Horan and Brown, 2009a).

Learning disability nursing practice has been at the forefront of leading new ways of working, service change and redesign. With an ageing learning disability nursing workforce, however, there is a need to ensure strategic influencing and leadership skills are developed and enhanced for the future.

As service models continue to evolve there will be a pressing need to support the development of leaders in learning disability nursing, with networking opportunities playing an important role (Horan and Brown, 2009). Ultimately, the future delivery of consistent and high quality care and support for people with learning disabilities, and their families and carers, will depend on highly effective succession planning (Northway et al., 2006).

Many LDNs have the personal qualities to take on leadership roles. To fulfil this potential, LDNs need to develop the necessary skills, including political influencing skills, to enhance services now and in the future.

However, changing service models have resulted in a reduction in local, regional and national leadership roles and opportunities for learning disability nurses. All of which impacts on the ability of LDNs to prepare for the all important future strategic leadership roles from which they can effectively campaign on behalf of people with learning disabilities, and provide a strong voice for LDNs.

## Key issues

- The reduction in strategic leadership roles in learning disability nursing.
- Identification of the career development opportunities in the third sector.

- Establish effective leadership and professional support wherever learning disability nurses practice.
- Ensure strategic leadership for all LDNs within the mixed care economy.
- Develop and utilise learning disability nursing networks across the UK to promote communication, professional development and support.

## The ways forward

- Support the development of leaders in learning disability nursing throughout the UK.
- Profile the role and contribution of leaders in learning disability nursing throughout the UK.
- Support the development of leadership for learning disability nurses practicing in the private sector.
- Promote the participation of learning disability nurses in leadership programmes and development opportunities.

Building on the RCN Learning Disability Nursing Summit, and the views and concerns expressed by other stakeholder organisations and RCN members, this paper captures the areas of priority that require action.

The RCN Learning Disability Forum, in collaboration with the UK Learning Development Consultant Nurse Network, will take the lead on behalf of members in the following areas:

## Education

1. The RCN Learning Disability Forum, in collaboration with other identified forums, will work in partnership with the Nursing and Midwifery Council to ensure the learning disability component of all pre-registration nursing programmes is fit for purpose.
2. Working with the RCN Education Forum and advisor, the RCN Learning Disability Forum will collaborate with education providers to review continuing professional development (CPD) opportunities for learning disability nurses wherever they may practice.

## Workforce

1. The RCN Learning Disability Forum will scope learning disability nurses (currently or previously registered) wherever they practice to establish an accurate workforce profile.
2. Working with key partners, the RCN Learning Disability Forum will develop an evidence base of the outcomes of learning disability nursing practice.

## Leadership

1. Work with the RCN Leadership and Management Forum and advisor to provide leadership opportunities for learning disability nursing.
2. Profile leaders in learning disability nursing wherever they may practice.

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