



**QUEEN'S
UNIVERSITY
BELFAST**

Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom an update.

Brown, M. (2014). Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom an update. Royal College of Nursing.

Queen's University Belfast - Research Portal:

[Link to publication record in Queen's University Belfast Research Portal](#)

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.



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



Contributors

2014 updated edition

Royal College of Nursing (RCN) Learning Disability Nursing Forum

Professor Michael Brown (Chair), Nurse Consultant, NHS Lothian and Professor of Health and Social Care Research

Professor Owen Barr, Head of School for the School of Nursing at University of Ulster

Anne Campbell, Operations Manager for Residential, Supported Living and Respite Learning Disability Services, Belfast Health and Social Care Trust

David Currie, Lead Nurse, covering Scotland and Northumberland for a national specialist third sector organisation

Simon Jones, Head of Behavioural Support, Care UK

Daniel Marsden, Practice Development Nurse with learning disabilities, East Kent Hospitals University foundation NHS Trust

Debra Moore, Group Director of Nursing, Quality and Governance, Danshell

Ann Norman, RCN Professional Adviser, Learning Disabilities and Criminal Justice

And:

Professor Ruth Northway, specialist adviser to the RCN Learning and Disabilities Forum, Professor of Learning Disability Nursing, University of South Wales

The RCN Learning and Disability Nursing Forum would also like to thank the following individuals for their contribution in developing the original edition:

Professor Owen Barr, Phil Boulter, Professor Barry Carpenter OBE, Professor Bob Gates, Denise Kelly, Betty Kershaw, Ian Mansell and Beatrice Nyamande.

The Royal College of Nursing (RCN) is the largest professional association for nursing in the UK. With around 415,000 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) 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, Professor 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.

References

- Alaszewski A, Gates R, Ayer S, Manthorpe G and Motherby E (2001) *Education for diversity and change: ENB research highlights*, London: English National Board for Nursing, Midwifery and Health Visiting.
- Anderson P and Doyle LW (2008) Cognitive and educational deficits in children born extremely preterm, *Seminars in Perinatology*, 32 (1), pp.51–58.
- Barr O and Gates B (2008) Education for the future: the changing face of education for staff, *Tizard Learning Disability Review*, 13 (1), pp.18–27.
- Barr O (2009) Learning disability nurse education: an opportunity to contribute to shaping the future, *Journal of Intellectual Disabilities*, 13 (3), pp.179–182.
- Blackburn C, Carpenter B and Edgerton J (2010) Shaping the future for children with foetal alcohol spectrum disorders, *Support for Learning*, 23 (3), pp.139–145.
- British Medical Association (2007) *Foetal alcohol spectrum disorders: a guide for healthcare professionals*, London: BMA.
- Cooper SA, Melville C and Morrison J (2004) People with intellectual disabilities: their health needs differ and need to be recognised and met, *British Medical Journal*, 239, pp.414–415.
- Department of Health (2006) *Modernising nursing careers: setting the direction*, London: DH.
- Disability Rights Commission (2006) *Equal treatment: closing the gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and mental health problems*, Stratford upon Avon: DRC.
- Emerson E and Hatton C (2007) Poverty, socio-economic position, social capital and the health of children and adolescents with intellectual disabilities in Britain: a replication, *Journal of Intellectual Disability Research*, 51 (11), pp.866–871.
- Emerson E and Hatton C (2008) *Estimating future need for adult social care services for people with learning disabilities in England*, Lancaster: Institute for Health Research, Lancaster University.
- Faugier J (2004) The predictions of nursing leaders, *Nursing Times*, 100 (4), pp.20–21.
- Gates B (2009) *The valued people project: report of a strategic review of educational commissioning and workforce planning in learning disabilities*, Newbury: South Central Strategic Health Authority.
- Gates, B (2010) When a workforce strategy won't work: Critique on current policy direction in England, UK. *Journal of Intellectual Disabilities*, 14 (4), pp.251–259.
- Healthcare Commission (2006) *Joint investigation into services for people with learning disabilities at Cornwall Partnership NHS Trust*, London: Healthcare Commission.
- Healthcare Commission (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*, London: Healthcare Commission.
- Horan P and Brown M (2009a) *Networking in intellectual disability nursing: an international perspective*, London: National Networks of Learning Disabilities Nurses.
- Horan P and Brown M (2009b) An international evaluation of networks and networking in learning disability nursing, *Journal of Learning Disability Practice*, 12 (8), pp.32–37.
- Jansen D, Krol B, Groothoff J and Post D (2005) People with intellectual disability and their health problems: a review of comparative studies, *Journal of Intellectual Disability Research*, 48 (2), pp.93–102.
- Kwok H and Cheung P (2007) Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities, *Current Opinion in Psychiatry*, 20 (5), pp.443–449.
- MacKay D, Smith G, Dobbie R and Pell J (2010) *Gestational age at delivery and special educational need: retrospective cohort study of 407,503 schoolchildren*, PLoS Med 7(6): e1000289.
- Mencap (2004) *Treat me right! Better healthcare for people with learning disabilities*, London: Mencap.

Mencap (2007) *Death by indifference: following up the 'Treat me right!' report*, London: Mencap.

NHS Health Scotland (2004) *The health needs assessment report: people with learning disabilities in Scotland*, Glasgow: NHS Health Scotland.

Northway R, Hutchinson C and Kingdon A (2006) *Shaping the future: a vision for learning disability nursing*, London: UK Learning Disability Consultant Nurse Network.

Nursing and Midwifery Council (2008) *The code: standards of conduct, performance and ethics for nurses and midwives*, London: NMC.

Parliamentary and Health Services Ombudsman (2009) *Six lives: the provision of public services to people with learning disabilities*, London: TSO.

Parrott R, Tilley N and Wolstenholme J (2008) Changing demography and demands for services for people with complex needs and profound and multiple learning disabilities, *Tizard Learning Disability Review*, 13(3), pp.26–34.

Royal College of Nursing (2007) *Shaping the future. A vision for learning disability nursing*. London: RCN. Available from www.rcn.org.uk/development/communities/rcn_forum_communities/learning_disabilities/news_stories/shaping_the_future_a_vision_for_learning_disability_nursing

Scottish Executive (2000) *The same as you? A review of services for people with learning disabilities*, Edinburgh: TSO.

Torr J and Davis R (2007) Ageing and mental health problems in people with intellectual disability, *Current Opinion in Psychiatry*, 20(5), pp.467–471.

Tyler F, Smith L and McGrother C (2007) Mortality in adults with moderate to profound intellectual disability: A population-based study, *Journal of Intellectual Disability Research*, 51 (7), pp.520–527.

United Kingdom Central Council for Nursing, Midwifery, and Health Visiting (UKCC) (2001) *Standards for specialist education and practice*, London: UKCC.

Resources and recommended reading

Royal College of Nursing (2006) *Meeting the health needs of people with learning disabilities: a guide for frontline staff*, London: RCN.

Royal College of Nursing (2007) *Mental health nursing of adults with learning disabilities*, London: RCN.

Royal College of Nursing (2010) *Dignity in health care for people with a learning disability*, London: RCN.

England

Department of Health (2001) *Valuing people: a review of services for people with learning disabilities in the 21st century*, London: DH.

Department of Health (2007) *Good practice in learning disability nursing*, London: DH.

Department of Health (2009) *Valuing people now: a new three year strategy for people with learning disabilities. Making it happen for everyone*, London: DH.

Department of Health (2009) *World class commissioning for the health and wellbeing of people with learning disabilities*, London: DH.

Department of Health (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities: a report by Professor Jim Mansell*, London: DH.

Michael J (2008) *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*, London: TSO.

Northern Ireland

Department of Health, Social Services and Public Safety (2005) *Equal lives: review of policy for people with learning disabilities*, Belfast: DHSS.

Scotland

Scottish Executive (2000) *The same as you? A review of services for people with Learning Disabilities*, Edinburgh: TSO.

Scottish Executive (2002) *Promoting health, supporting inclusion: the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities*, Edinburgh: TSO.

NHS Quality Improvement Scotland (2006) *Best practice statement. Promoting access to healthcare for people with a learning disability – a guide for frontline staff*, Edinburgh: NHS QIS.

NHS Quality Improvement Scotland (2009) *Tackling indifference: healthcare services and people with learning disabilities*, Edinburgh: NHS QIS.

Wales

Welsh Assembly Government (2001) *Fulfilling the promises: proposals for a framework for services for people with learning disabilities*, Cardiff: TSO.

Following the publication of *Learning from the past – setting out the future* (RCN 2011), the Royal College of Nursing (RCN) made the following pledge to people with learning disabilities and their families and work is on going:

- 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.

This pledge is important as 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 in specialist services (DH, 2012). There have been persistent concerns about the care and support of people with learning disabilities within

general health services. Government responses included *Six lives* (TSO, 2008), *Healthcare for all* (DH, 2008) and most recently the *Confidential inquiry into premature deaths of people with learning disabilities*. The Confidential inquiry reviewed the deaths of 247 people with learning disabilities over the two-year period and reinforced the need to identify people with learning disabilities in health care settings, and ensure the provision of ‘reasonable adjustments’ to ensure the needs of people with learning disabilities are most appropriately met and avoid serious disadvantage. The report stated that 42% of the 238 deaths, for which agreement of the overview panel was reached, were assessed as being premature (Heslop et al., 2013). It also highlighted that professionals must provide the same level of care to people with learning disabilities as to others, and avoid assumptions about quality of life or the appropriateness of medical, nursing or social care interventions, finding that the weakest elements related to problems with the diagnosis and treatment, thereby contributing to avoidable and premature deaths of people with learning disabilities. Collectively these investigations and inquiries all highlight the need for education and development to ensure that all practitioners, whether in general or specialist health services are aware of the needs of people with learning disabilities, and have the knowledge, skills and values to provide person-centred care that is appropriate to the abilities and needs of the individual and their family.

Developing learning disability nursing

The RCN and the Nursing and Midwifery Council (NMC) is fully supportive of the need for services to provide equity of access and outcome for people with learning disabilities and, as a result, all nurses need to have some knowledge about the nursing needs of children, adults and older people with learning disabilities and this is a requirement of all pre-registration nursing programmes. In addition, the need for nurses for people with learning disabilities to further develop their knowledge and skills in respect of physical and mental health was

also highlighted. Alongside this, across the United Kingdom nurses are specifically prepared to work with people with learning disabilities and there is recognition of the vital contributions made by learning disability nurses and health care support workers. The RCN supports the ongoing need for sustainable pre-registration learning disability nursing programmes across the United Kingdom and for the need to fully support the ongoing development of learning disability nursing and their important role in delivering person-centred care (RCN, 2007). To this end, learning disability nurses and health care support workers play a central role in the lives of people with learning disabilities and their families, particularly those with more complex care needs by:

- undertaking comprehensive assessments of health and social care needs
- developing and implementing plans of care
- working in collaboration with other professionals to meet health needs and co-ordinate 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 following sections provide an update on developments since the publication of *Learning from the past – setting out the future* (RCN, 2011) along with an indication of current areas requiring action. For ease of reference the key areas identified in the 2011 document are used to structure the discussion here.

Education

Progress to date

Within the NMC standards for *Pre-registration Nursing Education* (NMC, 2010) learning disability nursing has been retained as a specialist field of practice. In addition, in response to the Michael's Report (2008) which highlighted failures in the care of people with learning disabilities within acute care settings the NMC *Standards* (2010) require all nurses, whatever their field of practice, to achieve competencies in working with people with learning disabilities. The important input of learning disability nurses and the need for all nurses to be competent in meeting the health needs of people with learning disabilities has been further underlined in the *Confidential inquiry into premature deaths of people with learning disabilities* (Heslop et al, 2013).

Since the publication of the RCN (2011) position statement some universities have ceased to provide learning disability nursing courses and there has been a trend towards regionally based educational commissioning. Numbers of commissioned student places have, however, stabilised when compared with previous reductions and, in some areas, have begun to increase. There remains, however, a need to ensure that future commissioning is informed by both the demographic profile of the existing workforce and the changing demography and needs of people with learning disabilities. The knowledge and skills of LD nurses are increasingly valued by a range of social care, independent and third sector organisations but at present it is unclear as to whether current planning mechanisms capture the workforce requirements of these organisations. This is particularly important in the longer term as people with complex health needs are supported within social care settings where health care support may also be required. Only by taking this approach will sustainable models of educational commissioning be achieved that meet the needs of a range of service providers and support longer term viability of educational courses.

Linked to the changing configuration of service provision LD students are increasingly accessing

learning opportunities in a range of settings and sectors. These opportunities are essential since students need experience supporting people with a range of needs some of which are no longer the focus of direct care provision within the health service. In addition services outside of the health service also benefit from such student placements as they are then involved in developing the workforce for the future. This does, however, present some specific challenges in terms of preparation and updating of staff to supervise students since it may not always be feasible for staff from other services to be released to attend the preparation.

Arising from *Strengthening the commitment* (Scottish Government et al., 2012) a UK wide learning disability nurse academic network has been established and work is being undertaken by this group in collaboration with the Council of Deans to map current provision and to ensure sustainable programmes of educational provision.

Health care support workers form a valuable part of the nursing workforce and some may wish to access nurse education and achieve registration. All pre-registration courses are now provided at degree level and hence flexible routes are required to support health care support workers obtain (where necessary) the entry requirements for accessing an undergraduate programme.

The complex needs of many people with learning disabilities require nurses educated beyond preregistration level who undertake courses clearly linked to client need. Currently such education is required at postgraduate level for those practitioners qualifying with a first degree and also at first degree level for practitioners who qualified earlier and who need support to complete their degree. However, some challenges are evident in relation to post-registration education. Continuing professional development requirements, as well as financial constraints within health care organisations mean that practitioners are often faced with having to self-fund and/ or undertake education in their own time. From the higher education institution (HEI) perspective courses can only be delivered if there are sufficient student numbers and this can be challenging for any one HEI as the numbers of LD

nurses locally may be relatively small. All of these factors taken together give rise to the need for post- registration educational provision which is both flexible and addresses the range of academic levels.

Key issues

- The development and provision of educational courses needs to be informed by the needs of people with learning disabilities to ensure relevance to changing practice requirements.
- Educational commissioning requires collaboration across sectors to gain a meaningful understanding of current and future workforce needs.
- There is a need to ensure quality educational provision both in university and in clinical settings for all learning disability nursing students.
- There is also a need to ensure that all student nurses, whatever their field of practice, receive appropriate theory and practice experiences to equip them to effectively meet the needs of people with learning disabilities in the full range of health care settings. This is a particular concern in those universities who do not have a learning disability field programme and who may, therefore, not have learning disability lecturing staff.
- There is a need to develop flexible approaches to mentorship preparation to facilitate inclusion of potential mentors from across all sectors given an increasingly diverse range of student practice learning settings.
- Flexible routes to acquire the entry qualifications necessary to enter undergraduate nursing programmes should be developed for health care assistants (HCAs) and these should include appropriate recognition of prior experience.
- Flexible approaches are also required to the development and delivery of post registration courses to ensure accessibility and sustainability of courses. This may require collaboration between HEIs and differing approaches to course delivery.

The ways forward

- The implementation of the new pre-registration curriculum should be monitored to determine the extent to which it meets the changing needs of people with learning disabilities across a range of sectors. This should include monitoring of the provision of learning disability theory and practice within other fields of practice. Examples of good practice should be shared.
- The development of closer collaboration between service providers, educational commissioners and educational providers to ensure that both the numbers of commissioned places and the content of courses meet the needs of people with learning disabilities both now and in the future.
- The exploration of flexible approaches to HCA education, mentorship preparation and post-registration education ensure sustainability. This could usefully include collaboration between HEIs.
- Funding for post-registration education needs to be secured.

Workforce

Progress to date

It is difficult to comment definitively on progress in relation to the nursing workforce since accurate data remains difficult to obtain. This is due to a number of learning disability nurses working outside of the health service in a range of roles but who are not easily identifiable. What is known is that *Strengthening the commitment* (Scottish Government et al., 2013) indicated that a number of factors were likely to impact over coming years that would affect the ability of learning disability nursing to respond to rising levels and complexity of needs amongst people with learning disabilities. Included in these factors are the fact that numbers of student nurse places had fallen over recent years before now stabilising at a lower number than previously recorded, the current workforce is ageing and many have mental health officer status meaning that they

can retire aged 55, and the fact that many learning disability nurses work outside the health service but this does not seem to directly inform workforce planning. For example increasing numbers of learning disability nurses are being employed within the prison service. An additional factor that needs to be considered is that many of the staff likely to retire in the next few years currently hold senior positions in practice, education and research and hence it is not only personnel that will be lost but also valuable years' experience. Nonetheless in recent years some key learning disability nursing posts have been cut. For example this has occurred in relation to some nurse consultants.

Concerns thus remain as to whether there will be sufficient learning disability nurses with the right knowledge and skills working across the range of settings required. Issues relating to knowledge and skills have been addressed above and work is currently being undertaken across the UK to try and map the current learning disability nursing workforce. However, some key issues remain.

Key issues

- If an appropriate workforce is to be available to meet the needs of people with learning disabilities across a range of settings then there is an urgent need to identify current and future patterns of need and then to engage key stakeholders from across all sectors in working together to plan workforce requirements.
- Current exercises to map the existing workforce need to make every effort to identify those learning disability nurses working outside the health service in order to obtain more accurate data.
- Health care assistants undertake a range of important roles yet they are not included in the current mapping exercises.

Ways forward

- The current mapping exercises need to be expanded to include those learning disability nurses working outside the health service and also HCAs.

- Mapping of HCAs role and responsibilities
- The development of a mechanism whereby service providers from across sectors use this information along with clear evidence of current and projected client need in order to more accurately plan for a workforce that is appropriate both in terms of numbers and knowledge/skills.
- Succession planning is needed to ensure that before existing leaders retire younger colleagues are supported to develop their knowledge and skills.

Leadership

Progress to date

At the time the position statement was published in 2011 only limited attention had been given to the issue of leadership within the context of learning disability nursing. However, growing recognition of the inequalities in health experienced by people with learning disabilities, concerns regarding both workforce numbers and education, and the need to demonstrate outcomes from practice had added impetus to the need to develop clear leadership within practice, educational and research settings (Scottish Government et al., 2012). In addition, as noted above, a number of existing leaders within the profession are likely to retire over coming years and hence there is a need to focus on succession planning in relation to leadership.

The focus on leadership at all levels within *Strengthening the commitment* is welcomed and the process of developing this document has led to the development of new leadership opportunities. A leadership workshop for third year student nurses was held in July 2013 as part of the *Strengthening the commitment* programme and the academic network have a workstream focused on this area. Learning disability nurse leaders have become more visible taking up leadership positions in a number of key national forums and have been recognised within national awards. Their profile has been raised across the wider nursing profession through the use of social media. The

RCN have also been proactive in developing the award winning DVD that highlighted leaders at all levels across all four UK countries. Despite these important developments some key issues remain.

Key Issues

- There are few learning disability nurses working as directors of nursing in either the health service or the independent sector.
- There are few nurse consultants working in primary care, acute care and the independent sector
- Nurse leaders working in the independent sector are often not denominated as such.
- Learning disability nurses working across the range of sectors are often not identified as nurses.
- Further opportunities need to be taken to demonstrate and promote the outcomes of learning disability nursing practice.
- Learning disability nurses need to take opportunities to lead the agenda for driving up quality of care.

Ways forward

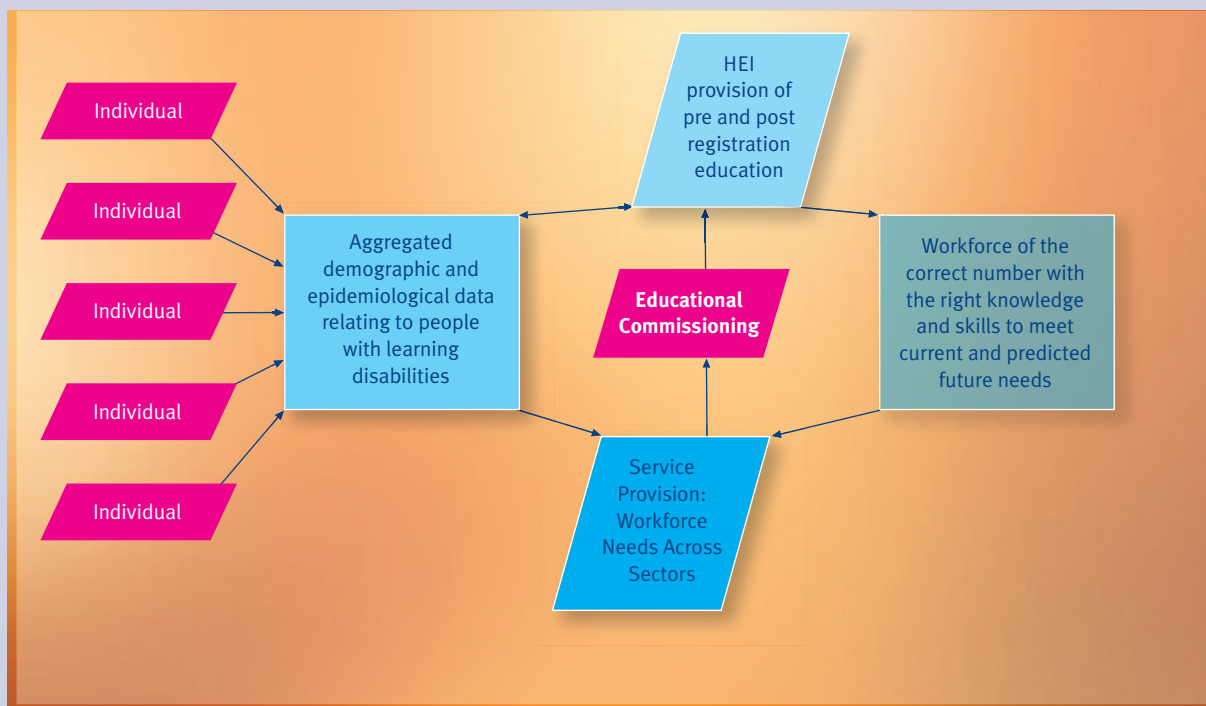
- Further work is required to increase the visibility of the leadership provided by learning disability nurses across sectors.
- *The RCN Principles of Nursing Practice* (2010) should be developed to illustrate how learning disability nurses demonstrate these principles in practice
- Learning disability nurses currently working in leadership positions need to be engaged in supporting the developing of other nurses into leadership roles.
- The role of the learning disability consultant nurse needs to be highlighted through, for example, their work in the development of the health equalities framework.
- The leadership role of learning disability nurses in the independent sector need to be both acknowledged and better understood.

Whilst the areas of education, workforce and leadership have been discussed separately here it

is evident that they are inter-linked and inter-dependent. Figure 1 (below) seeks to illustrate this by showing how client need needs to inform workforce planning and that both of these elements need to inform the development of

educational provision for learning disability nurses. Leadership is the glue that binds this together since strong leadership across sectors and at all levels is required to make this a reality.

Figure 1



References

Department of Health (2012) *Transforming care: a national response to Winterbourne View Hospital: Department of Health review final report*, London, DH.

Department of Health, Social Services and Public Safety (2005) *Equal lives: review of policy and services for people with a learning disability in Northern Ireland*, Belfast: DHSSPS.

Heslop P, Blair P, Fleming P, Hoghton M, Marriott A & Russ L (2013) *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Bristol: Norah Fry Research Centre.

Michael J (2008) *Healthcare for all: Report of the independent inquiry into access to healthcare for people with learning disabilities*. London: TSO.

Nursing and Midwifery Council (2010) *Standards for pre-registration nursing education*, London: NMC.

Parliamentary and Health Services Ombudsman (2008) *Six lives: the provision of public services to people with learning disabilities*, London, TSO.

Royal College of Nursing (2007) *Shaping the future. A vision for learning disability nursing*. London: RCN.

Royal College of Nursing (2011) *Learning from the past, setting out the future: developing learning disability nursing in the United Kingdom*, London: RCN.

Scottish Government (2012) *Strengthening the commitment: the report of the UK modernising learning disability nursing review*, Edinburgh: TSO.

January 2011, addendum March 2014

Published by the Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

020 7409 3333

www.rcn.org.uk

The RCN represents nurses and nursing,
promotes excellence in practice and shapes
health policies

Publication code 003 871
ISBN: 978-1-906633-63-9