Sustaining the Commitment

In 2011, the UK chief nursing officers initiated a review of learning disability nursing to ensure a focus and direction for registered learning disability nurses (RNLDs) and to highlight their longstanding commitment to this essential field of the nursing family. This resulted in the publication in 2012 of *Strengthening the Commitment* which set out a clear agenda to meet the challenge of making sure that people with learning disabilities across the United Kingdom had high quality support from RNLDs.

Throughout the review the four UK countries joined by the Republic of Ireland in the implementation phase worked closely with people with a learning disability, their families and carers, nurses and others to meet the challenge of making sure that people with a learning disability had the support that they deserved, needed and were entitled to in modern health and social care services.

Each country agreed to lead specific workstreams and meet regularly to oversee a programme of work. Much has been achieved throughout the programme including the sharing of good practice, nurturing of future leaders, structural changes in terms of networks, as well as products that have come out of the programme. Many of these are highlighted in *Living the Commitment* published in 2015 and include:

**The development and strengthening of networks**

The UK Learning and Intellectual Disabilities Nursing Academic Network (LIDNAN) was set up as an outcome of the work programme. The Network continues to flourish bringing together academics and practitioners from across the UK and the Republic of Ireland to support a robust academic and research base.

More RNLDs than ever before are using social media and communities of practice to share practice and experience, learning and supporting each other.

The UK Learning Disability Consultant Nurse Network continues to provide a focus for innovation and development across the UK countries. *The Health Equalities Framework* (HEF), an outcome measure was developed by members of the Network and is being used across the UK.

In Wales, following concerns about safety of care of people with a learning disability accessing acute care, a hospital care bundle was developed with the family of a deceased patient. The care bundle received greater attention due to the Strengthening the Commitment programme and has led to improvements in care and a greater understanding by general hospital staff. The family has gone on to establish the Paul Ridd Foundation that supports awareness training for champions in health care settings.
Leadership

As well as the high level leadership demonstrated by the chief nursing officers the programme enabled a number of student and newly qualified nurses to be developed and mentored either through involvement in the programme, individual mentorship or participation in the bespoke leadership programme that was delivered.

Promoting competence

A number of products were commissioned via NHS Education for Scotland during the programme, the work focuses on:

- improving health equalities for people by the development of the Equal Health Framework and associated learning resources
- supporting workforce development in Positive Behaviour Support and Active Support
- developing a range of resources to enhance staff's knowledge and skills in supporting people with learning disability who have complex care and support needs

The resources, which are available for wide use across the UK, can be found on the NHS Education for Scotland website and include:

- Learning Byte - Living Healthy Living Well
- Learning Byte - Postural Care
- Learning Byte - Breaking the Barriers
- Equal Health Educational Framework
- Equal Health Informed Practice DVD
- Equal Health Skilled Learning Resource
- Career and Development Framework for Learning Disability Nursing in Scotland
- National Framework for Pre-registration Learning Disability Nursing Field Programmes in Scotland
- Positive Behavioural Support: A Learning Resource
- Positive Behavioural Support: Facilitators Pack
- Thinking about me? Essential psychological care for people with learning disabilities
- Improving practice: supporting people whose behaviour is perceived as challenging
- Career Pathway for RNLD's in Northern Ireland
- Outcomes Based Resource Pack for Registered Nurses Learning Disabilities
Throughout, the programme has sought to strengthen the role of RNLDs recognising the benefits of having specifically prepared nurses to support people with learning disabilities.

As a consequence of the programme, progress has been made in strengthening the profession by ensuring networks that provide a platform to promote, share and develop the contribution of learning disability nurses, developing competence within the profession and across the wider health and social care system, providing outcome measures and resources to reduce health inequalities and strengthening leadership among learning disability nursing.

**Challenges that still need to be addressed**

It is now time to reflect on progress and consider the challenges that are still before us and in doing so reaffirm the important role that RNLDs have in supporting people with a learning disability and their families within the health and social care system.

We continue to face a number of challenges across the UK, including:

- recruiting and retaining the right number of RNLDs
- a need to build expertise across the health and social care systems to ensure reasonable adjustments are made and health needs identified and met
- complexity of services that can result in difficulties in accessing and navigating services
- some people with learning disability are remaining in hospital settings far longer than they should and are effectively living in an NHS bed and some people are receiving treatment a long way from home.

As a consequence, the support of RNLDs remains vital across the age range and in all settings. RNLDs play an important role in reducing the health inequalities that have all too often been experienced by people with learning disabilities. Going forward each country has their own programme of work through which the CNOs will continue to demonstrate their strong commitment to learning disability nursing. This document aims to act as a springboard to support the UK countries to continue to maintain the focus upon the needs of individuals with a learning disability and the importance of the role of the RNLD.
What next

In Wales

The Minister for Health and Social Services established a comprehensive review in February 2017. The review sought to assess how well public services in Wales identified and responded to the needs of individuals with a learning disability and their families/carers. The result of the review was the Learning Disability – Improving Lives Programme report published in June 2018. This report makes 24 recommendations across housing, health, education, transport and social care. The recommendations were fully supported by Cabinet and all sectors are now progressing work to deliver on these. There is a Ministerial Advisory Group in place to oversee the work.

Additional funding of £2m was announced in March 2019 to support the territorial Health Boards to strengthen capacity. This money is being spent on areas like acute and primary care liaison and to create a number of clinical lead posts Public Health Wales to support Health Boards in delivering on the health recommendations.

RNLDs have a role across all of the recommendations within Improving Lives, including:

- maximising the opportunities for RNLDs to work more effectively across the lifespan and particularly with children and around transition
- being able to offer a range of assessments and interventions that support people to live in their own homes and reduce the need for admission to specialist learning disability hospital settings
- supports the reduction of restrictive practices and inappropriate use of medication
- capitalising on the support RNLDs can provide in building expertise in the wider health care system to support people to have their health needs identified and met
- driving nurse led practice and advanced practice within learning disability services

Welsh Government is committed to ensure people who have a learning disability have access to a range of public services that will work seamlessly in partnership with them and their carers to enable individuals to live happy, healthy, fulfilling lives.

Professor Jean White CBE, Chief Nursing Officer (Wales)
In Scotland

The Minister for Mental Health, Minister for Older People and Equalities and Convention of Scottish Local Authorities (COSLA) launched the Keys to Life: implementation framework and priorities 2019-2021 in March 2019.

The framework is shaped by the Scottish Government’s National Performance Framework that sets national outcomes describing the kind of Scotland it aims to create.

The outcomes reflect the values and aspirations of the people of Scotland, are aligned with the United Nations Sustainable Development Goals and help to track progress in reducing inequality.

The outcomes most closely aligned with the Keys to Life are that people are healthy and active; respect, protect and fulfil human rights and live free from discrimination; grow up loved, safe and respected so that they realise their full potential, and live in communities that are inclusive, empowered, resilient and safe. Safe, effective person centred care is at the heart of health care in NHS Scotland.

The strategic outcomes of the Keys to Life are

- A Healthy Life: People with learning disabilities enjoy the highest attainable standard of living, health and family life.
- Choice and Control: People with learning disabilities are treated with dignity and respect, and are protected from neglect, exploitation and abuse.
- Independence: People with learning disabilities are able to live independently in the community with equal access to all aspects of society.
- Active Citizenship: People with learning disabilities are able to participate in all aspects of community and society.

The Chief Nursing Officer's long term strategy to shape the future of the nursing workforce is expressed in the Nursing 2030 vision and through Excellence in Care (EiC). EiC will ensure NHS boards and integrated joint boards have a consistent and focussed approach to measuring, assuring, reporting and improving the quality of nursing and midwifery care and practice.

The systems will inform quality of care reviews at national and local level, and drive continuous improvement in nursing and midwifery care. EiC quality measures for learning disabilities focus on opportunities for people with learning disabilities and the central role of RNLDs whose work and value base is often cited as good practice where people may experience difficulties in communication or experience stigma and discrimination.

RNLDs are central to reducing inequalities through direct interventions and working in partnerships, embedding collaborative working across multi-disciplinary, multi-agency and academic partnerships. This approach advocates person, family, carer, support networks which enable greater participation in care. The approach maximises the opportunities for RNLDs to work effectively in knowledge exchange and collaborative approaches within public health for people with learning disabilities,
such as increased access and participation in national screening programmes, early identification and prevention. It also improves access, participation and outcomes focus for people with learning disabilities to services such as health checks and epilepsy care plan review.

RNLDs have led the way in a number of modern health contexts, for example Modern Outpatient, Realistic Medicine, Lived Experience and Self-Management. They have used a quality management approach to identify areas of improvement and ensured an equal focus on building on strengths. They have developed a shared leadership model resulting in an ‘Exceptional’ Healthcare Improvement Scotland Rating for ‘Leadership’, European Foundation Quality Management 5 star award, and multiple national and international recognitions with recurring themes of innovation, safety and person centred model of care. RNLDs have also significantly contributed to reviews of incapacity law and practice, and the review of learning disability and autism in Scotland’s Mental Health Act.

In Strengthening the Commitment, Scotland committed to lead for the four nations on work on positive behaviour support and interventions by RNLDs. Positive Behaviour Support (PBS) is core to the work of learning disability nursing: using behavioural technology and person centred values to understand the function or cause of the behaviour of concern. PBS brings together values, theory and process to support people. NHS Education Scotland has developed and hosts a range of PBS learning resources.

Our future vision for RNLDs is that they will:

- be central to the development of Trauma Informed Care and complementary approaches to service delivery for people who have a learning disability with complex needs

- consider how best to contribute to the knowledge, skills and attributes the current and future workforce across NHS Scotland need, sharing their learning and experience of practice which is sustainable and progressive, focusing on prevention, early intervention and enablement to support people to continue to live well in their own homes and communities;

Shape and influence national policy development, stepping into an enhanced leadership role to continue to model person centred approaches across NHS Scotland

Fiona McQueen, Chief Nursing Officer (Scotland)
In England

As Chief Nursing Officer for England, I recognise how the *Strengthening the Commitment* and accompanying guidance, has provided the four countries of the UK with a common framework to raise the national profile of learning disability nursing and to help shape learning disability nursing practice. I see the guidance as an important enabler for change, clearly illustrating the contribution and impact of this valuable branch of nursing and recognising the vital work done by learning disability nurses every day to support people and their families.

As we progress the NHS Long Term Plan in England, it is a time of opportunity for learning disability nurses, and for those aspiring to pursue a career in this field. Our commitment to increase incentives for those entering pre-registration nursing will support the explicit ambition to increase the number of learning disability student nurses and the recent announcement to increase funding for continuing professional development will support those in practice to further enhance their expertise.

I am very much committed to ensuring learning disability nursing remains a priority. Delivering improved care and improved outcomes will require greater cohesion across the nursing workforce, with learning disability nurses leading the way in reducing health inequalities and supporting nursing colleagues across all sectors to deliver our collective aims for people and their families. It will be important that learning disability nurses are more fully integrated into the wider workforce and are recognised as key enablers within the multidisciplinary team.

The recent celebrations to recognise 100 years of learning disability nursing showcased an amazing array of innovation and I have personally committed to build on the success of this by supporting several initiatives to help sustain the positive profile of the profession.

As we look towards the next 100 years, I believe learning disability nursing will continue to gain prominence, with the expertise of learning disability nurses being actively sought across health and social care. Fundamentally, learning disability nurses will always remain expert ambassadors and advocates, ensuring people’s voices are heard, their rights upheld, and their access to high quality care ensured.

Ruth May, Chief Nursing Officer (England)
**In Northern Ireland**

Northern Ireland has a ten year plan to transform its health and social care system including improving the lives of those 40,177 people living in NI with learning disabilities.

In January 2017, the NI devolved government collapsed however despite the absence of a sitting Executive or Assembly, NI currently continues to work within the context of the Ministerial direction set out by a previous Health Minister in 2016 in the document Health and Wellbeing 2026: Delivering Together.

A major aim in NI’s draft Programme for Government is for the people of NI to ‘enjoy long healthy, active lives’. The Department of Health is the lead agency for delivering this outcome. Research shows that people with learning disabilities do not enjoy equal opportunity in living long and healthy lives. The research has also repeatedly highlighted the mortality gap and health inequalities they experience.

The Chief Nursing Officer for Northern Ireland is sustaining her commitment to develop, strengthen and grow the scope of practice and role of RNLD’s in Northern Ireland through a range of work streams. As part of this commitment the Chief Nursing Officer has commissioned a number of strategic projects which are specific to nursing for people with a Learning Disability including:

- asking the Public Health Agency to progress a phase of the Delivering Care Policy Framework for Nursing and Midwifery Staffing in Northern Ireland focusing on Learning Disability Nursing (Hospital and Community). The Delivering Care Policy Framework aims to support the provision of high quality care which is safe and effective in hospital and community settings through the development of a framework to determine staffing ranges for nursing workforce

- commissioning a Review of Nursing for people with a Learning Disability in Northern Ireland

- commissioning the Foundation of Nursing Studies to facilitate a bespoke Creating Cultures Programme for RNLD’s working across Northern Ireland

- commissioning a regional professional development forum for RNLD’s. This forum was launched in March 2017 and is jointly led by NIPEC and RCN NI. To date, the forum has facilitated seven learning events which were attended by an average of 50 RNLD’s from across the region

- commissioning NIPEC to develop a specific Practice Assessment Document for Learning Disabilities nursing students in Northern Ireland in preparation for the Future Nurse Future Midwife NMC Education Standards Northern Ireland implementation
In addition, the Department of Health in Northern Ireland have;

- retained the bursary for undergraduate nurse training in Northern Ireland. Places for undergraduate training for learning disabilities nursing students were increased by 33% in 2018-19 and increased by a further 25% 2019-20, taking the total number of undergraduate training places for learning disability nursing up to 50

- commissioned the Health and Social Care Board to develop a new Regional Model for Adult Learning Disability Services in Northern Ireland

- undertaken to implement the first phases of The Mental Capacity Act (Northern Ireland) 2016 in October and December 2019. The Mental Capacity Act (NI) 2016 is a progressive piece of legislation that, when fully commenced, will fuse together mental capacity and mental health law for those aged 16 years old and over within a single piece of legislation, as recommended by the Bamford Review of Mental Health and Learning Disability

All the work being progressed to improve the lives of people living with learning disabilities is happening against a backdrop of serious allegations of abuse at Muckamore Abbey Hospital, NI’s main hospital for people with learning disabilities which is currently the subject of a large-scale police investigation. This has been an extremely turbulent time for patients, their families and staff working in Learning Disability services. The Chief Nursing Officer for Northern Ireland is committed to a culture of learning and quality improvement. The findings and associated learning from this investigation will undoubtedly be a further driver for change and reform.

These work streams, and the outcomes of ongoing and future reviews will inform and set out the roadmap for the transformation and development of new services for people with a learning disability and the future role of RNLD’s.

The Chief Nursing Officer and the Department of Health’s vision is to ensure that everyone living in Northern Ireland will enjoy long, healthy, active lives; and to ensure that people get the right care, of excellent quality, at the time of need as outlined in the Draft Programme for Government. Achieving this requires transformation across the Health and Social Care system. RNLD’s will have a central role to play in helping to deliver this vision.

Professor Charlotte McArdle, Chief Nursing Officer (Northern Ireland)
Conclusion

Strengthening the Commitment and Living the Commitment has provided the four countries with a framework to raise the profile of learning disability nursing and to shape learning disability nurse practice. The development of networks and connections across the four countries has ensured that the voice of learning disability nursing is heard and the value and impact of the profession is recognised. A great strength has been the work that the profession has done in working with people and their families and this is a partnership that we endorse as each country progresses forwards with their plans to continue to strive for excellence.

It is an exciting time for learning disability nursing, there is a strong social movement promoting the profession and national groups advocating and leading discussions on the future role of learning disability nursing. This has led to increased employment opportunities across a greater variety of settings and an increase in demand for learning disability nurse training. We are committed to listening, hearing and taking action to support the delivery of learning disability nursing across the four countries and will continue to work closely with colleagues to build the capability and capacity of the workforce. We recognise that there have been challenges in recruiting to learning disability nurse training programmes and we are in support of the actions to promote learning disability nursing as a profession and in support of the national commitment to invest in the workforce.

We recognise that learning disability nursing has faced many challenges. The most significant of these has been in the failure of care for some of the most vulnerable people. Learning disability nurses are committed to challenging poor, discriminative and abusive practice and we are committed to standing with the learning disability nursing workforce to promote abuse free care that promotes the welfare of people and their families. We welcome a greater cohesion across the nursing workforce to reduce health inequalities and promote positive outcomes for people with learning disabilities.

As the celebrations of 100 years of learning disability nursing are coming to an end, it is important to reflect on where learning disability nursing has come from and to look beyond the horizon to the future role of learning disability nursing. Strengthening the Commitment and Living the Commitment has demonstrated the work that has been undertaken to affect the some of the changes needed to make a difference to people's lives and each of the countries has stated their ongoing pledge to further evolve the workforce by identifying priorities to continue with this work in line with national policy and developments. Moving in to the next decade learning disability nurses must continue to be ambassadors, working with people, their families and communities to promote and advocate for the rights of people with learning disabilities to receive the health care they need.
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