

# Connecting for Change: for the future of learning disability nursing

CLINICAL PROFESSIONAL RESOURCE



# Acknowledgements

The RCN would like to express sincere thanks to the members from across the UK and the stakeholders who we work in collaboration with who have supported us in developing this publication.

The RCN would like to give a special acknowledgement to Annie Norman who is retiring this year. Annie has been the College's Professional Lead for Learning Disabilities for the last 15 years. She has provided leadership and support to our members who are learning disability nurses, and supported developments across the UK to improve the lives of people with learning disabilities. Annie has been instrumental in the development of this report.

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This document has been designed in collaboration with our members to ensure it meets most accessibility standards. However, if this does not fit your requirements, please contact [corporate.communications@rcn.org.uk](mailto:corporate.communications@rcn.org.uk)

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## Foreword

The word “challenging” gets used a lot in learning disability nursing. People we support may present with what may be considered “challenging behaviours” and COVID-19 has certainly presented “challenging times”.

Although challenges can sometimes be seen as uncomfortable, they are often challenges we want to accept as they provide the opportunity for incredible achievements. For example, consider how you might challenge yourself to run a marathon. Challenging behaviour provides an opportunity to grow a deeper understanding about how people communicate and express their needs. COVID-19 has presented the opportunity to develop creative solutions for working differently.

It would be apt to describe current times as challenging for registered nurses in learning disabilities, and it would be fair to say they have been so for some time. It has varied across the four UK countries, but there have been concerns about a decline in the number of learning disability nurses and student learning disability nurses. We have also seen the unacceptable and repeated uncovering of abuse and poor practice in some services for people with learning disabilities. These are examples of challenges that learning disability nurses are determined to address.

Alongside the challenges, we have also seen new opportunities develop. This report is titled *Connecting for Change*, and in compiling it, it has been evident that connecting people is a strength of the profession. There are many examples of learning disability nurses working together across the countries in the UK and across all settings. There are many diverse and exciting roles where learning disability nurses are connecting with people with learning disabilities and their families to ensure equity of access, the upholding of rights, and ensuring people are receiving quality care that improves lives and opportunities.

We have seen new NHS roles develop, such as hospital liaison nurses and nurses working in intensive support teams. We believe there is an increase in learning disability nurses working in social care settings. We are also seeing the solid establishment of learning disability nursing roles in other settings, such as prisons and services for people with dementia.

In 2019, we celebrated 100 years of learning disability nursing. It has been clear from these celebrations how much the lives of people with learning disabilities have changed in this time. It is therefore no surprise that the roles of learning disability nurses have changed too, and we recognise that more change is needed.

What remains clear is that the unique combination of skills, knowledge, and values of learning disability nurses remain needed. However, it can at times feel like our skills and roles are not understood. Whilst in the past we have played a crucial role in the closure of long stay hospitals, and pioneered activity to promote community inclusion for people with learning disabilities, it has not always been clear where the vision for learning disability nursing in the 21<sup>st</sup> century is moving towards. We need to continue connecting to strengthen a vision for learning disability nursing for the future.

This is our challenge. There is some amazing work going on across the four nations of the UK to take on this challenge! On behalf of learning disability nurses and the RCN Learning Disability Nursing Forum, I am grateful to the RCN for setting out here its

dedication to learning disability nursing and its commitment to support the exceptional work that is happening within the landscape of the current challenges.

Together we are connecting to address the challenges of contemporary learning disability nursing.



Jonathan Beebee

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RCN Learning Disability  
Nursing Forum Chair



Glenn Batey

Acting Chair, RCN Learning  
Disability Forum

## About this publication

This publication focuses on registered nurses in learning disabilities. This is the smallest of the four fields of nursing, representing 2.3% of nurses on the Nursing and Midwifery Council's (NMC) register (Nursing and Midwifery Council, 2020a). The term learning disability nursing has been used throughout this publication to describe the field of practice of registered nurses in learning disabilities.

Learning disabilities are commonly defined by a severe impairment of intellectual functioning. This is generally accepted as having an IQ score below 70, although services are relying less on IQ scores in contemporary practice. A score of 70 indicates the person is in the lower second centile of normal distribution, so referring to 2% of the population. An IQ score alone does not define a learning disability. The needs must have been present before the age of 18, therefore affecting formative years. The person must also have significant adaptive skills deficits, needing support in order to survive (World Health Organization, 2010). The term learning disability has been used in the UK since the 1990s. Internationally, the term intellectual disability is used. Learning disability nursing is a unique field of nursing as a pre-registration pathway in the UK and Republic of Ireland, and most other countries do not benefit from this skilled professional field at point of registration.

In recent times, it has become commonplace to refer to “people with learning disabilities and/or autism”. The needs of people with autism who do not have a learning disability are very different to the needs of people with a learning disability. Discussing the needs of people with autism and the needs of people with learning disabilities together risks doing neither group justice. Both groups deserve their own individual attention. Whilst some learning disability nurses may be skilled in, and support, people with autism who do not have learning disabilities, many nurses are not. For this reason, we have avoided using that term throughout this publication in acknowledgement that this will not adequately address the experiences of people with autism when they do not have learning disabilities. This publication focuses on the work of learning disability nurses for people with learning disabilities, which may include people with autism who also have learning disabilities. It does not focus on the abilities and needs of anyone who does not have a learning disability unless specifically stated.

In 2016, the RCN's *Connect for Change* report (Royal College of Nursing, 2016) highlighted that the numbers of learning disability nurses employed by the NHS in England had fallen by 33% during the preceding five years. Five years on from that report, this downward trajectory has continued and since 2009 the number of learning disability nurses employed by the NHS in England has fallen by 42.1% (NHS Digital, 2021). We have also seen how the changes to the way students are funded in England threatened the future of learning disability nursing programmes and subsequently the future of the profession. The previous report only focused on challenges in England. This publication is reviewing issues in all four UK countries and aims to reflect challenges and opportunities across the UK.

Whilst acknowledging the challenges learning disability nursing is facing, we must recognise that concerns about the falling numbers of learning disability nurses and learning disability nursing career pathways are being heard, and stakeholders are taking action. There are examples of positive action being taken by government departments across the UK, and these efforts are beginning to make a difference. This work is

recognised in this publication and recommendations are made to support this work to continue the progress made.

This publication explores contemporary issues concerning the field of learning disability nursing practice and sets out a series of recommendations and priorities that the UK government and devolved administrations must address. It also identifies priorities for the RCN to take forward.

Ultimately, there must be enough highly skilled learning disability nurses across all roles and settings to respond effectively to the needs of current and future demands, and the profession must be relevant for the contemporary abilities and needs of the people it supports. This includes considering the increasing demand on health and social care services and how services are changing. Learning disability nursing needs to have equitable recognition as a critical field of nursing practice, and investment in its direction to ensure people with learning disabilities have access to learning disability nurses who are competent and capable in supporting them.

# Learning disability nursing in the UK

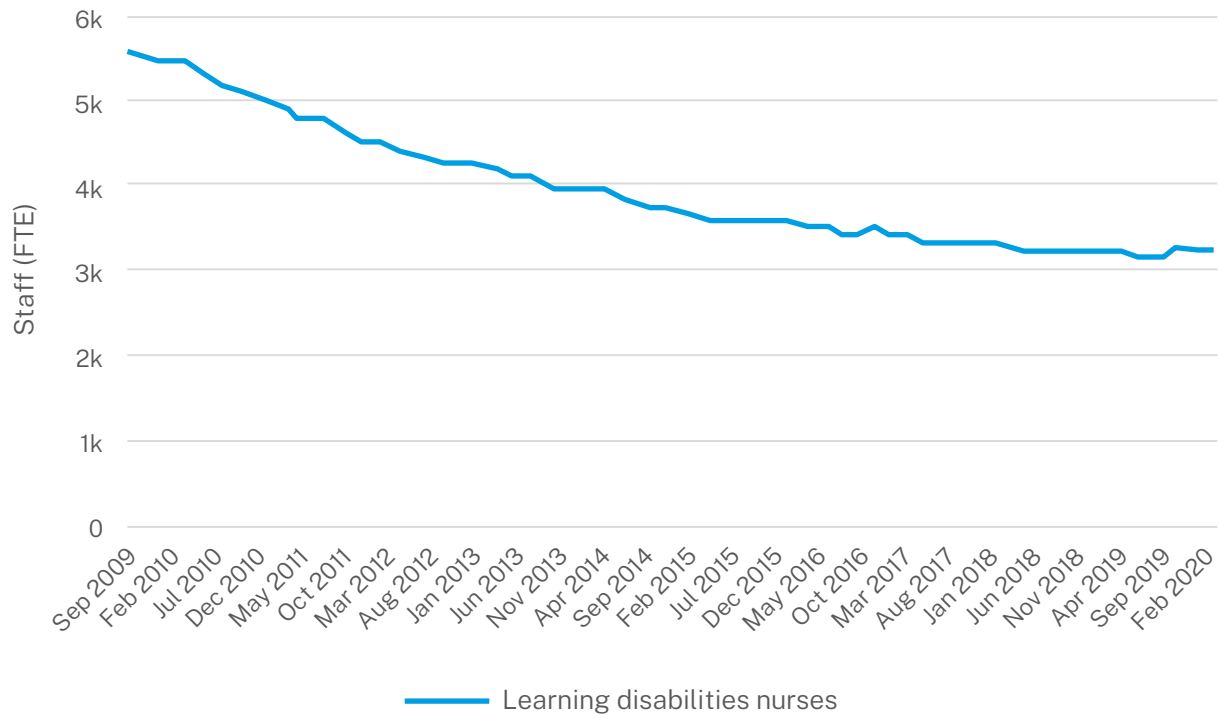
2019 marked the centenary of learning disability nursing as a recognised and registered field of practice. Those 100 years have seen huge changes in how people with learning disabilities live their lives and the support and systems available to meet their needs. The support for people with learning disabilities has progressed from large congregated models of care towards prevention of admissions, integration into mainstream services, and community-based support. Similarly, the roles of learning disability nurses have also changed in conjunction with support redesign. This centenary was celebrated by learning disability nurses across the UK and highlighted the achievements of the profession in providing care and support to people with learning disabilities (for example, University of Chester, 2019).

Whilst there is a lot to celebrate, there are continuing concerns regarding the challenges that people with learning disabilities face and the future of learning disability nursing. The decline in the number of learning disability nurses has continued in the five years since the first RCN *Connect for Change* report and we are now seeing 40% fewer learning disability nurses in the NHS in England since May 2010, from 5,368 in May 2010 to 3,217 in July 2020 (UK Parliament, 2020). Similarly, in Scotland, there has been a 25% reduction in learning disability nurses in NHS settings over the less than five-year period between March 2015 and December 2019 (from 1,399 to 1,048 nurses). This part of the nursing workforce in Scotland currently carries a 4.3% vacancy rate, a high percentage of which (13%) have been vacant for three months or more (TURAS Data Intelligence, 2020). Interestingly, these reductions have not been seen in Northern Ireland or Wales.

This pattern of decline in the learning disability nursing workforce goes back further than the last 10 years. A 2011 report to the Department of Health in England highlighted a catastrophic drop in numbers of learning disability nurses and forewarned about a continuing pattern of decline. The numbers of NHS employed learning disability nurses dropped by over 50% from 12,504 in 1995, to 6,600 in 2009 (Gates, 2011), to now just over 3,000 learning disability nurses employed by the NHS in England (UK Parliament, 2020). These workforce patterns may reflect the changing service models for people with learning disabilities, with an increase in social care solutions replacing health provisions. However, it is not known if the numbers of learning disability nurses employed in social care settings have increased in line with this.



## Learning disability nurses working in the NHS in England



Recent data from the NMC (Nursing and Midwifery Council, 2021a) indicates that across the UK there has been a small decrease in the number of learning disability nurses registered to practice. There were 17,503 learning disability nurses in 2017, which reduced to 17,128 (-0.3%) in March 2021. This decrease is not consistent across the UK and is primarily seen in the data for England. Understanding the true extent of the challenge the learning disability nursing workforce is facing is further compounded by significant gaps in workforce data.

- There are over **17,000** registered learning disability nurses on the NMC register.
- There are just over **3,000** of those working in the **NHS in England**.
- There are just over **1,000** in the **NHS in Scotland**.
- There are just over **400** in the **NHS in Wales**.
- There are just over **300** working in **health and social care in Northern Ireland (HSCNI)**.
- **There is an absence of clear data about where the remaining 12,300 registered learning disabilities are working.**

There is limited other information available to identify where the nurses who do not work for the NHS/HSCNI are. We do not know if they remain in clinical practice or where they are currently employed. This incomplete picture limits opportunities to identify accurate workforce activity and needs. It means we do not have a genuine picture of what is really happening, and we cannot accurately describe the skills, knowledge, and competence

the workforce needs for their practice. It means it is not possible to say with confidence if there is a shortage of learning disability nurses with the evolving service models, or where the impact of any shortages of the learning disability nursing workforce will be felt greatest. Essentially, we are unable to take a longitudinal approach to continuing professional development (CPD) to ensure workforce capacity and capability, and education and training is secured.

There is some encouraging provisional data from Skills for Care (Skills for Care, 2021) that suggests there are up to 5,000 nurses working in learning disability social care settings in England. We know that in recent times social care provisions provided by government health bodies have transferred to independent/third sector social care providers, and it may be that nurses have simply moved from NHS/HSCNI settings when these services have moved to social care providers. Yet there are no known strategies across the UK to support nurses in social care settings for people with learning disabilities in terms of education, recruitment, leadership, and development. It appears that the lives of people with learning disabilities and the practices of learning disability nurses have evolved, yet our data and strategies about this field still need to catch up.

There has also been a steep decline in the number of applicants and acceptances to pre-registration learning disability nursing courses. This has primarily been seen in England where applications to learning disability nursing courses were 45% lower in 2019 compared to 2016, and acceptances to these courses were 35% lower (Learning Disability Today, 2018). A 2018 UK-wide survey by the Council of Deans highlighted that over 50% of universities that educate learning disability nurses are considering terminating these courses as, due to diminishing numbers, they were not financially viable (Nursing Times, 2018). In Northern Ireland, Scotland and Wales, where there are still central commissioned training places and bursaries for students, there are still too few places being commissioned to keep up with rising demand for learning disability services. For example, in Wales, numbers of student places in learning disability have remained largely static for several years (Royal College of Nursing, 2020). Student learning disability nurse places are based upon workforce planning, which is based upon NHS/HSCNI needs and does not capture the needs of the social care workforce.

# Key health challenges for people with learning disabilities

It is beyond the scope of this publication to detail all of the challenges people with learning disabilities may face. The focus here is on what we believe are some of the most common challenges and those with the largest impact on people's health and wellbeing.

## Health inequalities

People with learning disabilities face shocking health inequalities that are difficult to comprehend in modern society.

- Life expectancy for women with learning disabilities is 27 years lower than for women in the general population and 23 years shorter for men.
- Only 38% of people with learning disability will live beyond the age of 65, compared to 85% of the general population.
- People with learning disabilities face increased risk of avoidable death, with 50% of deaths being from either a treatable condition or a preventable occurrence (University of Bristol, 2021).
- 97% of people with a learning disability have other co-existing conditions such as physical health conditions, mental health issues, epilepsy and physical impairments (National Institute for Health and Care Excellence, 2016).

There are some health needs that people with learning disabilities experience at a higher rate than the general population. These include:

- respiratory disorders
- constipation and other gastro-intestinal disorders
- endocrine disorders
- congenital heart problems
- certain cancers such as leukaemia
- premature aging including early onset dementia
- obesity.

Public health initiatives, such as the Improving Health and Lives Public Health Observatory (National Development Team for Inclusion, 2020), have supported research into the prevalence of these inequalities in order to identify health promotion initiatives to address these.

The causes of these health inequalities are complex and multi-faceted. Some causes of learning disabilities are accompanied by biological or genetic factors that increase health risks. A learning disability commonly affects someone's ability to understand communication and express themselves, with 90% of people with learning disability experiencing a communication difficulty (Royal College of Speech and Language Therapists, 2013). Similarly, the symptoms of health problems can be difficult for some people with learning disabilities to comprehend and articulate. These characteristics can make it difficult for people to seek health interventions and describe symptoms.

Most people with learning disabilities will also experience multiple socio-economic risk markers that make them more vulnerable to health needs, such as being unemployed (Mencap, 2021) and relying upon benefits and having limited social networks. Health services can be poorly designed to meet the environmental requirements that some people with learning disabilities need, and not equipped with the skills required to make the reasonable adjustments that would enable equitable access to health care (Mencap, 2017).

### Examples of learning disability nurses addressing this need:

- Learning disability nurses in community-based learning disability services often support people with learning disabilities to access primary and secondary health care. They can promote communication between the person and their support and the health care setting. It is common for learning disability nurses to promote the use of hospital passports/health profiles by those supporting people with learning disabilities to ensure health care teams have easy access to important information.
- Learning disability liaison nurses work directly in many hospital settings as a source of expertise for hospital staff and promoting a bridge between hospital and community services.
- Some hospital departments have directly recruited learning disability nurses to have their expertise directly on their team. For example, neurology departments have recruited learning disability nurses and provided training to support them to become sapphire nurses, enabling them to work as epilepsy nurse specialists in clinics that commonly see people with learning disabilities.
- There are many learning disability nurses working as part of learning disability mortality reviews, using their expertise to review deaths of people with learning disabilities and ensure that lessons are learned.
- There are many examples of social care provisions for people with complex health needs that directly employ learning disability nurses to ensure their health needs are understood and consistently met. This includes specialist residential and supported living services.

### Areas for improvement

- Community learning disability teams have faced significant cuts since austerity began in 2010 in the UK (Aikaterini Malli et al., 2018). This has led to the number of learning disability nurses employed in these teams being reduced, services being re-designed and nurses redeployed, and the activity of community teams changing its focus. It was previously commonplace for learning disability nurses in community teams to provide adapted health promotion interventions. Much of this work has been cut with the expectation on general health services to make reasonable adjustments without the expertise that learning disability nursing offers. Re-investment in these teams is needed to counteract the cuts these teams have faced over the past 12 years.
- The availability of learning disability liaison nurses remains inconsistent (Health Education England, 2020). There are differences in the availability of these roles, with many hospitals still not having access to this resource, and wide variations in provision for primary care services. Where they are available, there remains difference in the seniority these nurses are given, affecting the leadership these roles have. This must be addressed and was highlighted in the previous *Connect for Change* report where we called for liaison nurses in all hospitals.

# Supporting people who present challenging behaviours

Approximately 15-20% of people with learning disabilities who are known to learning disability services have presented with behaviours that can challenge others or affect their independence (Bowring et al., 2019). These can include physical harm to others, physical harm to themselves, intimidating/verbally challenging behaviours, and damage to property. The term “challenging behaviours” reflects that these behaviours are often to meet an unmet need and are not malicious in nature, whilst acknowledging they are challenging for the person themselves and those who experience them.

It has been known for a long time that community support for people with learning disabilities is not good enough (Department of Health, 2007) and there have been many reports that state what services are needed (for example, NHS England, 2015a and 2015b).

The Care Quality Commission’s *The State of Health Care and Adult Social Care* report for 2019 (Care Quality Commission, 2019) highlighted the impact of shortages in nursing upon quality from their inspections in England. Focusing specifically on specialist hospital settings for people with learning disabilities, they found that quality of care was significantly impacted upon by shortages of learning disability nurses. Recruitment and retention continue to be a significant challenge in health and social care settings making it difficult to train and retain a skilled workforce. However, the registration and regulation of social care workers is believed to be improving retention in health and social care in Northern Ireland, Scotland, and Wales (Nuffield Trust, 2020).

In order to provide effective and lasting interventions for people with learning disabilities who demonstrate challenging behaviours we need a skilled workforce with an in-depth knowledge of learning disabilities, a sound understanding of behaviour science principles, and strong clinical leadership (PBS Academy, 2015). Without this people with learning disabilities will continue to receive inadequate social care and inappropriate hospital care. These inadequate services present risks of being unnecessarily and overly restrictive at best, and severely abusive at worst (Care Quality Commission, 2020). The appalling abuses that have been publicly uncovered at Winterbourne View, Muckamore Abbey Hospital, and Whorlton Hall bring much needed attention to the abuses that people with learning disabilities can face. They highlight vulnerabilities in the systems which can allow unsafe practices and abuse to flourish in some inpatient settings. Sadly, these are the latest in a long history of abusive exposés that people with learning disabilities have faced, and although these tragic situations are usually exposed in hospital settings, we know they can happen in all support settings.

### Examples of learning disability nurses addressing this need

- Many areas across the UK have developed intensive support teams as part of their community services for people with learning disabilities. These teams aim to bridge the gap between hospitals and the community to prevent admissions and promote effective discharges. Learning disability nurses are an essential component of these teams, and many are nurse led.
- Some learning disability nurses, particularly those working in intensive support teams, pursue Masters level training in applied behaviour analysis/positive behaviour support. This ensures their levels of skills and knowledge are aligned to international standards for certified behaviour analysts, which enables them to provide positive behaviour support to the highest level of clinical competence.
- There are social care providers that are employing learning disability nurses to provide clinical leadership and evidence-based interventions to people with learning disabilities who show challenging behaviours to ensure effective social care. Nursing presence in these services also promotes multi-agency working with community learning disability services.

### Areas for improvement

- The term positive behaviour support continues to be applied loosely with various levels of competence and clinical application permitted to prevail (Beebee et al., 2015). Standards must improve in order to achieve high quality and effective support for people with learning disabilities who show challenging behaviours. Learning disability nurses are ideally positioned to lead on improving these standards.
- Commissioning of learning disability social care does not actively ensure their local provider market includes services that have strong nursing leadership from learning disability nurses. This perpetuates the skills gap between health and social care settings.
- There remains a void between hospital services and support in peoples' own homes, and a continued division between statutory provisions and services provided by independent or third sector provisions. This leads to admissions when support breaks down and delays in discharges.
- There is inconsistent provision of intensive support teams to prevent people's support at home breaking down and promote effective discharges from specialist hospital services. Where they do exist, there is variety in the multidisciplinary make-up of these teams, and some teams work 9-5 Monday to Friday whilst others have better round-the-clock availability.
- There has been a welcomed government direction in all four countries to close hospital beds for people with learning disabilities. However, it is acknowledged that there will be times when a hospital admission is still necessary. Too often this hospital care is not led by learning disability nurses, which results in poorer quality care (Care Quality Commission, 2019).

# Supporting people who have committed or are at risk of committing offences

People with learning disabilities account for 7% of the prison population in England and Wales, and over 30% of the prison population has learning disabilities or difficulties, with similar patterns apparent in Scotland and Northern Ireland (Prison Reform Trust, 2021). Prisons are mandated for the purpose of both justice and rehabilitation. Often prisons fail to meet their duty to provide rehabilitation for people with learning disabilities, with most of the offending behaviour programmes they offer requiring an IQ of 80 or above to participate (Her Majesty's Inspectorate of Probation, 2015).

People with learning disabilities are also extremely vulnerable in these settings (Foundation for People with Learning Disabilities, 2012) and often struggle to fulfil their rights in all criminal justice settings. For example, they can be vulnerable to suggestion, coercion and acquiescing during interviews, and they may not know how to instruct a solicitor.

People with learning disabilities may be diverted from criminal justice settings under mental health legislation to secure hospital settings. The number of secure inpatient beds has reduced as part of hospital closure plans, but the need for appropriate support for this vulnerable group remains (Royal College of Psychiatrists, 2013).

The line between what is offending behaviour and what is challenging behaviour can be grey, with intent to offend and mental capacity often the defining characteristics. Learning disabilities are often accompanied by social disabilities, with social rules and laws not being understood. This can result in their actions towards others being perceived as offensive. People can be vulnerable to suggestion and keen to please others, which can lead to them becoming involved in criminal activity. Poor socio-economic status and limited social networks can also impact upon these vulnerabilities.

Many areas have now developed services that provide earlier intervention through a roll out of liaison and diversion support models that can reconnect people to services and plan care to avoid imprisonment as a first option. These teams primarily sit within mental health provisions, with most referrals relating to meeting the needs of people with mental health needs in the criminal justice system (RAND Europe, 2016). Some of these teams have strategically included the role of a learning disability nurse in these service designs (NHS England, NHS Wales, 2013, Emerald Insight). There are also examples of community learning disability teams having nurses with expertise supporting those who are at risk of criminal justice services contact (Royal College of Psychiatrists, 2014).

The aim of criminal justice liaison services is to divert people away from the criminal justice system. Diversion may mean being diverted to a secure specialist learning disability hospital under mental health legislation with criminal justice restrictions. These restrictions can make discharge from hospital difficult to achieve and can result in longer hospital stays than a prison term would have been.



### Examples of learning disability nurses addressing this need

- Some health and justice liaison teams have appointed learning disability nurses to ensure they have the skills needed to address the needs of people with learning disabilities in custody and court settings and support appropriate diversion.
- Some community learning disability services include “forensic” teams that often include learning disability nurses. These teams may provide adapted offender behaviour management programmes, clinical risk assessment and management plans for offending risks, and liaison with criminal justice systems to ensure adequate offence management in the community. In some areas, where there is not enough demand for this at a local level a regional resource has been developed.
- There has been an increase in learning disability nurses working in prison settings. They ensure rights are promoted and met, provide adapted offending behaviour management programmes, and ensure that complex health needs are identified and met (for example, G4S, 2018).
- There are examples of specialist social care provisions for people with learning disabilities who are at risk of contact with criminal justice services that are nurse led.

### Areas for improvement

- There is inconsistency in the support available to people with learning disabilities in criminal justice settings, with the provision of learning disability nurses often relying on local commissioning decisions and service leaders identifying this as a need (Centre for Mental Health, 2019). Consistent provision of support is required.
- Community learning disability services for people at risk of criminal justice contact vary in their skills mix and geographical coverage. Whilst some of this may be related to local/regional needs there is a lack of assurance that people can access the same level of support regardless of their address (Health Education England, 2017).
- Improvements are required in early identification and intervention services for people at risk of encountering criminal justice services and an increase in effective social care provisions.

# People with profound and multiple learning disabilities

The abilities and needs of people with profound and multiple learning disabilities can be extremely complicated. They will have profound learning disabilities and frequently other complex conditions, such as physical disabilities, sensory impairments, sensory processing difficulties, complex health needs, and mental health needs (Doukas et al., 2017). There can be intensive and ongoing physical health needs requiring direct and delegated nursing tasks, such as:

- PEG feeding
- suctioning of oral secretions
- physiotherapy for respiratory and mobility needs
- urinary catheter management
- complex epilepsy management.

They may have challenging behaviours including self-injurious behaviours that serve as communication or sensory functions. Many people with profound and multiple learning disabilities die in childhood, though many are now living longer into adulthood, and as this trajectory continues to increase the number of people with complex needs continues to increase, with additional complexities as they age (University of Bristol, 2021).

Many people with profound and multiple learning disabilities have limited or unconventional methods of communication. Their life experiences, their needs, and what they need from their support system can be extremely different to those who are better able to express their needs. Mental health needs are suspected to be high for this group but diagnosis can be hard due to difficulties in conventional methods of displaying symptoms. Yet, when consulting with experts by experience there is often little recognition of the need to ensure the views of these people and their families is represented, meaning those with the highest levels of needs are at risk of being least heard (The Challenging Behaviour Foundation, 2021).

People with profound and multiple learning disabilities often require complex integrated support from health and social care services and strong partnership working with families in order to ensure they can live their lives to the fullest and have the optimum quality of life. Achieving a high quality of life includes meeting their complex health needs, promoting effective communication, providing meaningful engagement and enabling them to have an active role in their local communities (Doukas et al., 2017).

### Examples of learning disability nurses addressing these needs

- Children's hospices provide vital support for families of young people with profound and multiple learning disabilities and there are examples of learning disability nurses providing leadership and health interventions in these settings.
- Learning disability nurses can be found in clinical and leadership roles in social care settings for people with profound and multiple learning disabilities. This can include working in nurse-led supported living or residential care settings and nursing home settings. They may also take the role of registered managers in these teams using clinical skills for management and leadership.
- Community learning disability nurses provide an essential bridge between people living at home, whether with family or in social care, and primary and secondary health care services. They also play a vital role in ensuring the coordination of multidisciplinary support from the wide range of allied health professionals who may be involved.
- Learning disability nurses work in statutory health commissioning and case management roles to ensure skilled assessment of people's needs are made and that support is effectively commissioned.

### Areas for improvement

- Consultations and developments need to engage people with learning disabilities. The abilities, needs and views of those with profound and multiple learning disabilities should be sought and included.
- The roles of learning disability nurses working in these settings seldomly receives the attention of other learning disability nursing roles. The vital contribution made by nurses in this setting should be considered and included in strategic planning at local, regional and national levels.

# Children and young people

Identifying that a child has learning disabilities may happen prenatally, at birth, or as the child misses key developmental milestones. For some, a learning disability may be acquired, for example by trauma, before they reach 18 years old. For families, discovering that their child has learning disabilities can be a difficult time. They may feel a sense of grief for the loss of the hopes they had for their child and may struggle to achieve diagnosis and access the support they need for their child and themselves.

Health and social care systems can be complicated and difficult to navigate, so it can be hard for families to access the support that they need and the support their child needs to thrive. Children with learning disabilities may experience all of the health challenges mentioned in this report. They will experience the same health inequalities, with more children with complex needs living into adulthood. Children with learning disabilities will have needs relating to challenging behaviour and are disproportionately represented in criminal justice settings (Council for Disabled Children, 2017). Evidence has shown that early intervention can promote better outcomes in terms of long-term independence, better health outcomes, maintaining loving family home environments, and reductions in long-term support needs (Challenging Behaviour Foundation, 2021). Yet the provision of support is varied across the UK (Council for Disabled Children, 2017).

Many families find transitioning from children's services to adult's services extremely difficult (Brown et al., 2020). They experience care moving from being family-centred to being person-centred and the focus on parental involvement can shift. The structure of support is also very different when moving to adulthood meaning care can feel uncoordinated.

## Examples of learning disability nurses addressing this need

- There are learning disability nurse-led respite and children's hospice provisions that provide essential breaks for families and provide reassurance that complex health needs can be met when their child is away from the family home.
- Some areas have children's community learning disability teams that have learning disability nurses as a core component, providing direct intervention and support to children and their families and supporting complex care co-ordination.
- There are learning disability nurses working in transitional roles supporting children and families during this challenging time.
- Specialist education provision and pupil referral units may have provision of school nursing and other nursing interventions, such as emotional and behavioural support. There are examples of learning disability nurses working in these roles.

### Areas for improvement

- The provision of children's community learning disability nursing support is inconsistent across the UK.
- There is often a lack of strategic direction for transition planning and, where it exists, the role of learning disability nursing in this is not clearly defined.
- School nursing provision is in need of review, and the role of learning disability nursing in this requires consideration and direction.

# Neglecting the human rights of people with learning disabilities

The abuses uncovered in settings such as Whorlton Hall and Muckamore Abbey Hospital highlight that the abuse and neglect of human rights for people with learning disabilities is a systemic issue. It is a cultural issue that is ingrained in society and becomes amplified in settings without strong leadership, that in turn fails to reflect the values and actions to promote human rights (Care Quality Commission, 2020). The scandal and exposure of abuse in learning disability services continues to recur time and time again.

These horrific abuses are usually exposed in learning disability hospital settings where support should be highly governed. However it is essential that it is acknowledged that abuse like this can happen in any setting for people with learning disabilities.

Society does not treat people with learning disabilities as equally valued members of their communities.

*“The standard you walk past is the standard you accept”*  
Lieutenant General David Lindsay Morrison, 2013

When communities consider it acceptable to use terms that currently, or previously, were used to describe people with learning disabilities as the worst words that can be used to insult someone, this reflects a culture that people with learning disabilities are viewed as the “worst” in our communities. When comedians consider people with learning disabilities to be easy laughs for their sets then we create a culture where it remains acceptable to mock people and laugh at their expense. We create a culture where people with learning disabilities are given no value and no dignity.

This acceptance then leads to further degrading treatments. 73% of people with learning disabilities report experiencing a hate crime (Dimensions, 2017), and the reality is this figure is likely to be much higher. Blanket DNACPR decisions are made regionally for all people with learning disabilities (Care Quality Commission, 2021). Undignified and inhumane care becomes prevalent and normalised (Care Quality Commission, 2020). It therefore should not be surprising that where there is poor leadership in health and social care settings, these cultures and these practices further develop into abusive actions. What is unacceptable is that these cultures continue to develop when this is known.

## Examples of learning disability nurses addressing these needs

- There are examples of learning disability nurses working as part of safeguarding teams and in advocacy services.
- There are learning disability nurses pioneering human rights-based approaches to support provision and risk management.
- There are learning disability nurses who work in leadership positions driving positive cultures and positive approaches to supporting people with learning disabilities.

### Areas for improvement

- Strong and competent leadership skills are needed across the learning disability nursing workforce.
- More learning disability nurse leadership positions are needed in health and social care settings to provide career pathways and to provide leadership of human rights-based cultures.
- Shortages of learning disability nurses need to be addressed, particularly in settings where a clear correlation has been found between quality and learning disability nursing presence.
- Planning is needed for how learning disability nurses can be strategically utilised across all services to ensure human rights are protected and promoted.

# The impact of COVID-19 on people with learning disabilities

The COVID-19 pandemic has brought into sharp focus the disadvantage and inequity experienced by people with learning disabilities. The numbers of people with learning disabilities dying due to COVID-19 was estimated to be six times the rate of the general population, and 30 times higher for those aged 18-35 (Public Health England, 2021). People with learning disabilities have also been dying at a younger age from COVID-19. Deaths have been spread more widely across the age range of the population with learning disabilities than the general population. The largest numbers linked to COVID-19 among people with learning disabilities was among those aged 55-64 compared to over 75 for the general population.

A 2020 report by Mencap (Mencap, 2020) highlighted the unclear and inconsistent guidance during the pandemic which led to unsafe practices, including the lack of clarity over whether people with a learning disability can be accompanied to hospital. This in turn led to unmet support needs for individuals who did not have the right person with them to provide support and assist with communication.

These emerging issues of inequities and disadvantages faced by people with learning disabilities during the pandemic are deeply concerning and bring to the forefront the injustices that people with learning disabilities face. COVID-19 has provided a tragic but unique situation that demonstrates these issues. Lessons must be learned so that the same injustices are not allowed to continue. The pandemic has highlighted the importance of reasonable adjustments and appropriate provision that need to be in place to support equity of health outcomes and to ensure people's mental, emotional and physical health needs are met. This includes the need for sufficient numbers of learning disability nurses who can work with, and advocate for, the individual across all health and care settings.



# The UK policy context

Health and care are devolved matters in the UK. The commissioning of learning disability services and workforce are the responsibilities of the individual countries. However, given our shared values base and the shared challenges facing learning disability care and the learning disability nursing workforce, a four-country approach has proven to be a helpful opportunity to share best practice and develop policy.

Between 2011 and 2019, the UK chief nursing officers (CNOs) led a review of learning disability nursing across England, Scotland, Wales, and Northern Ireland. This resulted in the publication of *Strengthening the Commitment* (Scottish Government, 2012) which set out a UK-wide approach to ensuring people with a learning disability had access to high quality support from learning disability nurses. Areas for action included strengthening capacity and capability of the workforce as well as improving the quality of care provided by learning disability nurses.

Each UK nation developed local implementation steering groups to respond to the recommendations of the report. The final updated report (Scottish Government, 2019a) detailed the future plans for each of the UK nations, and the CNOs once again highlighted their 'longstanding commitment to this essential field of the nursing family'. It was noted by the CNOs that, whilst a four-country approach was no longer considered necessary at this time by the respective Departments for Health, some universal challenges persisted. For example:

- the recruitment and retention of the right numbers of learning disability nurses
- a continuing need to create expertise across and within health and social care systems, to ensure the health needs of people with a learning disability are identified and addressed in a rights-based, person centred manner
- a recognition that complex configuration of services can result in people having difficulties accessing and navigating services
- some people with learning disabilities remain in specialist inpatient assessment and treatment unit settings, often far away from their friends and family, for longer than they should; in effect, they end up living in hospitals.

Given the challenges highlighted by the four UK CNOs, we are concerned that there will be slowing momentum in the years after the programme has come to an end at a time when there is a need for sustained and focused activity. Cross-country collaboration has been hugely beneficial throughout the *Strengthening the Commitment* work, for example in the sharing of good practices. As a small field of nursing collaboration is essential in achieving maximum impact.

# Country-specific challenges and opportunities

There are commonalities regarding the provision of learning disability nurses across the four UK nations. However, there are also important contextual differences. It is beyond the scope of this publication to provide in-depth analysis of the differences here, however key points are given to demonstrate some of the variety in activity and needs in each of the four countries.

## England

When the bursary for nurse education was removed in 2016 in England, there was a decline in student applications for all fields of nursing but learning disability nursing was hardest hit. It has long been recognised across the UK that learning disability nursing student education applicants are typically older than applicants for other fields of nursing (Council of Deans, 2017) and therefore potentially have greater financial commitments. The more mature student group was felt to be hardest hit by the decision in England to remove the bursary (Stewart, 2018). Whilst the bursary type funding was subsequently reintroduced, costly university fees were believed to continue dissuading people from pursuing this career option.

In response to continuing concerns regarding declining numbers of learning disability nurses, Health Education England announced an investment of £2m in July 2019 (Health Education England, 2019). This included funding for increased pre-registration training, including registered nurse degree apprenticeships for learning disability nursing; the development of 150 trainee nursing associate posts; and a national programme to promote increased awareness of the career. This increased funding and planning has made a difference with student numbers increasing from 349 in 2018 to 509 in 2020 (UCAS, 2020). However, it is not clear yet if this additional funding will be permanent and if this improvement will be sustained.

In August 2020, additional funding was provided for learning disability nursing apprenticeships (Ely, 2020). This has enabled some social care providers who may have never been able to support employees through this career development path to take this opportunity, as well as make the opportunity more achievable for NHS trusts.

An *All England Learning Disability Nursing Plan* (NHS England, 2020) was introduced in 2020, jointly lead by NHS England and Health Education England. This plan has been focused on attracting, retaining, developing, and celebrating learning disability nursing. The *All England Learning Disability Nursing Plan* provided the impetus for greater collaboration which needs to be sustained if we are to be efficient and effective in addressing the challenges the profession faces.

NHS England and Health Education England are currently developing post-qualifying education packages for learning disability nurses. These are looking to develop nurses' skills in primary and secondary care liaison; community forensic support and intensive support; and specialist learning disability inpatient nursing. These courses are separate to, but could potentially be part of, a pathway align with the NMC's UK-wide review of the specialist practice qualification (Nursing and Midwifery Council, 2021b).

## Wales

The *Improving Lives Programme* (Welsh Government, 2018) is a transformation programme hosted by Improvement Cymru. The programme was launched in 2018 following a Welsh Government review of how services for people with learning disabilities could be strengthened. This cross-Government programme is working on three priority areas:

- to reduce health inequalities – through reasonable adjustments to general health care services and access to specialist services when needed
- to improve community integration, including increasing housing options closer to home, integrated social care, health and education, and increased employment and skills opportunities
- to enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness.

This programme is overseen by the Learning Disability Ministerial Advisory Group.

An additional £2m investment was announced in March 2019 (Welsh Government, 2019) to support health boards in increasing meeting the health needs of people with learning disabilities. This funding is for a three-year plan to:

- reduce the inappropriate use of medication and restraint through increasing the use of a range of evidence-based interventions such as positive behaviour support
- improve the take up and quality of annual health checks offered by GPs to people with a learning disability
- improve the capability and capacity of acute hospital care to make reasonable adjustments enabling people with a learning disability to access mainstream services
- to ensure that people with complex needs have timely and easy access to learning disability specialist services including trauma/crisis, the full range of accommodation including secure provision and out of hours access
- implement the specialist and mainstream school nursing framework – a set of evidence-based standards for nursing in schools.

These improvements should make a real difference in people's lives, improve outcomes and reduce health inequalities.

The role of learning disability nurses in this work is clearly essential and plans for Wales to deliver this include the key development of new National Learning Disability Programme Lead in Public Health Wales, as well as an increase in primary and acute learning disability nursing posts.

In 2020, the *Once for Wales Health Profile* (Improvement Cymru, 2020) tool was launched. This enables essential health information to be held by people with learning disabilities, ensuring that this is available for health appointments. The document covers how to best communicate with the person, key health information, and any reasonable adjustments that may be required and is available in both Welsh and English to ensure it engages fully with the Welsh communities.

In Wales, nursing student numbers are decided by the Welsh Government. Unfortunately, the number of commissioned student learning disability nursing placements in Wales has remained static at 77 places for the last three years. There is only one learning disability consultant nurse in Wales and the RCN has called for this to be increased to ensure there is one such post in every health board. The RCN is calling for the Welsh Government to ensure a nursing workforce plan to accompany the strategic development of learning disability services in Wales over the next decade.

## Scotland

The Scottish Government has an existing programme of work on autism and learning disabilities. This programme includes *The Keys to Life: unlocking futures for people with learning disabilities, implementation framework and priorities 2019-2021* (Scottish Government, 2019b) which is overseen by the Scottish Commission for People with Learning Disabilities. The programme also includes the *Scottish Strategy for Autism*, which is approaching the end of a 10-year plan, with the latest update being the *Scottish Strategy for Autism: outcomes and priorities 2018-2021* (Scottish Government, 2018). The Scottish Learning Disability Observatory (University of Glasgow) also provides information on health issues for people with learning disabilities in Scotland, informing policy decisions and service improvements.

The Scottish Government and COSLA have recently published the *Towards Transformation* report which builds on the existing programmes. It sets out a revised plan for the next two years based upon what challenges have arisen through the COVID-19 pandemic and what the engagement activities have taught them so far (Scottish Government, 2021a). This report commits to considering a commissioner for learning disabilities and piloting nurse consultant roles for autism and learning disabilities.

An independent review of learning disability and autism in the Mental Health Act in Scotland reported to Scottish Ministers on 18 December 2019. In the RCN's representation (Royal College of Nursing, 2019a) to the review, we highlighted the role of learning disability nursing, which provides crucial, specialist care, support and treatment in collaboration with people who have a learning disability, their carers and their families. Despite this, there has been a 10% reduction in learning disability nursing staff in NHS Scotland over the past two years. Learning disability nursing also currently carries a 3% vacancy rate (Royal College of Nursing, 2019a).

However, Scotland has continued to offer nurse training with no tuition fees and an increased bursary of £10,000 per annum. This has led to a 51% increase in student learning disability nurses in the last year (Scottish Government, 2021b).

Going forward, it is clear that learning disability nursing will have a key role to play in supporting people with learning disabilities. However, as we noted in our letter to the review, there are already vacancies in the current workforce, and it is not clear what the optimum workforce is to realise the ambitions of the various policies and reviews. The latest available NHS National Education for Scotland figures (to 1 December 2019) (TURAS Data Intelligence, 2020) show a 4.3% vacancy rate in NHS Scotland alone.

## Northern Ireland

Northern Ireland developed a *Modernising Learning Disability Nursing Action Plan* (Department of Health, Social Services and Public Safety, 2014) as part of the Strengthening the Commitment work, alongside a *Learning Disability Services Framework* (Department of Health, Social Services and Public Safety, 2015). In support of this work, a regional collaborative for learning disability nurses was set up by the CNO and a professional development forum has been established. Both these groups have representation from statutory and independent sector providers. The regional collaborative issues regular communiques and has undertaken a number of projects which include developing a *Career Framework for Learning Disability Nursing* (Department of Health, Social Services and Public Safety, 2014) an outcome-based resource pack for learning disability nurses, and draft key performance indicators for people supported by learning disability nurses (Department of Health, Social Services and Public Safety, 2015).

The four country report *Sustaining the Commitment* highlighted that in Northern Ireland, the number of people pursuing learning disability nursing degrees increased by 33% in 2018-19 and by a further 25% in 2019-20 (Scottish Government, 2020). Nursing bursaries have been maintained in Northern Ireland.

An independent review of learning disability nursing has been commissioned in Northern Ireland and the Foundation of Nursing Studies has facilitated a bespoke *Creating Cultures Programme for learning disability nurses* (Foundation of Nursing Studies).

Following reviews of governance and leadership at Muckamore Abbey Hospital (Department of Health and Social Care, 2020), a public enquiry is being planned. Nursing shortages and the involvement of nurses in multidisciplinary decision making have already been highlighted in the reviews to date as areas requiring improvement.

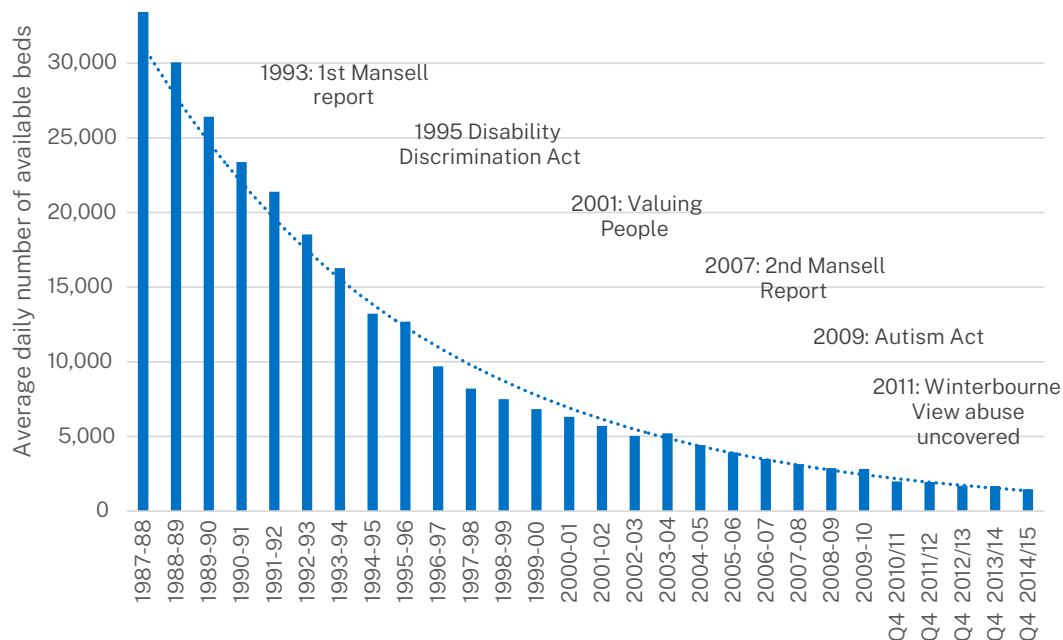
# Conclusions

Registered nurses in learning disabilities began in the large hospital settings of the early 20th century. As the health and social care sector has evolved, so have learning disability nurses. However, whilst we only know for sure where a small proportion of learning disability nurses are working, can we know for sure what learning disability nurses in the 21st century are doing?

NHS England’s *Transforming Care Plan* detailed that they intended to close 50% of specialist learning disability nursing hospital beds (NHS England, 2015b). Many learning disability nurses work in these settings, and whilst there is clear direction of the services that are not wanted, there is a lack of clear plans for where learning disability nurses’ skills are intended to be used instead. There is a lack of a clear road map for the profession and career pathways. Government administrations in all four UK countries do not identify how many learning disability nurses they need across health and social care settings and there is a lack of clarity regarding what roles these professionals are required for.

The table below illustrates how learning disability inpatient beds in England have significantly reduced from 1987 to 2015. This change has been reflected across all four UK countries. The change reflects how support for people with learning disabilities has transferred from health settings to social care settings. What is not clear is whether the funding has followed people from health to social care and many local councils are under financial pressure to cut spending on learning disability support.

## NHS learning disability beds since 1987



On a positive note, new roles are developing in learning disability nursing but there is a lack of consistency and co-ordination of these roles (Health Education England, 2020). For example, acute learning disability liaison nursing roles began to emerge around 2010 but these roles do not exist in all acute hospitals and the positions vary in their availability, leadership responsibilities and role remit.

Source: NHS England: [www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf](http://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf)

One of the challenges for learning disability nursing today is the breadth of roles they fulfil and the small number of nurses in these roles (Rose, 2021). Often there are regional variations to their scope, remit, and function which makes it increasingly difficult to define learning disability nursing and plan its progression. Greater clarity in the role and career pathways is needed to support the recruitment to learning disability nursing (Council of Deans, 2017).

The knowledge, skills, and values of learning disability nurses have been embraced by a wide range of health and social care settings, many of which are in services that are not specifically for people with learning disabilities (Rose, 2021). This could include further diversifying the role of learning disability nurses. Learning disability nurses are already seen in autism services, support for people with acquired brain injuries, dementia, stroke, and mental health services. If this diversity of learning disability nurse roles is to be expanded upon formally, pre-registration education will need to ensure students are consistently provided with education and experiences to achieve competency.

Learning disability nursing in the UK is at a critical phase in terms of workforce development, leadership and education. Learning disability nurses at times feel that their contribution, to both the population they serve and nursing more broadly, is overlooked (National Development Team for Inclusion, 2020). This is at least in part because they are the smallest of the four fields of nursing in the UK. Based on the number of NMC registrants they represent just 2.3% of nurses registered and their numbers are decreasing (Nursing and Midwifery Council, 2020b). Learning disability nurses report their roles are at risk of being misunderstood, undervalued and under-represented nationally (National Development Team for Inclusion, 2020).

The nursing workforce in general is facing a staffing crisis. Recent figures indicate there are over 43,000 vacancies in the NHS across the UK (National Audit Office, 2020) and there is no readily available corresponding data concerning the private and independent sectors. These workforce shortages result in unsafe staffing levels, impacting on patient safety and the safety and wellbeing of nurses (Mid Staffs NHS Foundation Trust Public Inquiry, 2013). Governments across the UK must urgently invest in attracting increased numbers of entrants into the profession, as well as retaining those experienced staff, to address the severe and increasing staffing shortages. Learning disability nursing represents a significantly at-risk section of the nursing workforce, and by reviewing the variations in approaches to funding for learning disability nurse education across the UK can highlight what is working and what increases risks to recruitment.

Current workforce planning needs to improve its effectiveness, While Scotland, Wales and Northern Ireland already have safer staffing legislation, this does not extend to England. All UK countries need to ensure health and social care providers understand and are accountable for the workforce decisions they make. This should include all types of health and social care provision, both within and outside the NHS/HSCNI. The RCN has recently published *Nursing Workforce Standards* (RCN, 2021) to support nurses and employers to review what is required for safe nursing practice in their setting. This will be a valuable resource for supporting workforce decisions.

All services must make reasonable adjustments for people with learning disabilities. Learning disability nursing is clearly a reasonable adjustment that can ensure people with learning disabilities have equity in access to health and social care and their human rights

are upheld. To ignore the role of learning disability nurses is discrimination by proxy. Commitment is required to ensure the role of the learning disability nurse is understood and a planned part of future provisions.



# The RCN's ongoing commitment to learning disability nursing

The RCN is committed to working within the RCN strategic framework focusing on:

- staffing for safe and effective care and the nursing workforce standards
- the independent health and social care strategy
- RCN education strategy.

As part of this work the RCN:

- commits to developing with stakeholders a career framework for learning disability nurses. This needs to include competency standards aligned to different roles. Priorities for competency standards include:
  - primary and secondary liaison learning disability nursing
  - positive behaviour support
  - supporting people who are in contact with health and justice services
  - specialist learning disability inpatient nursing
  - children's learning disability nursing and transition to adulthood
  - leadership and human rights-based nursing.
- is committed to promoting and producing evidence of the impact of learning disability nursing roles and practice
- will continue to highlight and amplify evidence from all four UK countries regarding any gaps between learning disability nurse availability and the needs of the community across all settings
- will use evidence to influence the devolved governments to ensure the progression and sustainability of learning disability nursing roles and practices across all settings. This will include showcasing and sharing good practice as well as advocating for Government administrations to oversee the identification and development of clear career pathways for learning disability nursing
- will continue to lobby UK governments to ensure that there is equity for people with learning disabilities as a vulnerable and disenfranchised group and promote the human rights of people with learning disabilities across health and social care settings, in line with the Congress resolution of 2019 (Royal College of Nursing, 2019b) we will champion learning disability nursing as an ambassador for the human rights of people with learning disabilities
- is committed to strengthening collaborations with expert by experience groups and external stakeholders to further improve the quality of learning disability support. This will include expanding collaborations to ensure the voices of people with learning disabilities are included
- will lobby the Nursing and Midwifery Council (NMC), strategic planners, and employers to identify and record where learning disability nurses on the NMC register are working and recognise the contribution of the profession in a diverse range of work settings

- will ensure equity of emphasis on members working in all settings to reflect the learning disability workforce and represent their views fully. This will be done through proactive engagement with members and employers across health and social care
- will influence and collaborate with system leaders and devolved governments to lead on learning disability nursing specific pre-registration recruitment and retention, supporting universities and health and social care providers
- will highlight the need for leadership and career pathways in the profession, and the impact on reductions in leadership roles. This will be essential in leading positive human rights-based cultures, supporting clinical governance, quality assurance, safe and effective practices, and career development. This will include support for current leaders, developments in the current workforce, and plans for leaders of the future.

# What the RCN is asking of the Government administrations across the UK

- **Human rights**

Current systems permit the abuses seen at places such as Winterbourne View and Muckamore Abbey Hospital to repeat again and again. Government administrations in all four UK countries must progress learning disability strategy directives to take urgent action to address the systemic breaches to human rights that people with learning disabilities face.

*Responsibility: Health and Social Care Ministers*

- **Ministerial leadership**

Government administrations in all four countries should identify a responsible minister and/or commissioner for to take responsibility for the agenda of addressing the needs of people with learning disabilities. This has already been called for by charities in Scotland who are calling for a commissioner for learning disabilities (Our Voice Our Rights). A report in England post-Winterbourne View called for the same (NHS England, 2014), whilst the CQC has called for a single point of ministerial leadership (Care Quality Commission, 2020).

*Responsibility: Health and Social Care Ministers*

- **Learning disability nurse career framework**

Strategic planning is urgently needed for where learning disability nursing skills are required, including consideration for the diversity of roles for where learning disability roles are now and where they may be in the future. This needs to be across health and social care settings, in both NHS/HSCNI settings and private/independent settings. It is essential that each country continues to strategically plan how the needs of people with learning disabilities will be addressed, and what the roles are for learning disability nurses in these plans.

*Responsibilities: Strategic workforce planning authorities, commissioning authorities and leaders*

- **Social care planning**

Greater emphasis should be given to the role identity and progression for learning disability nurses working in nursing roles in social care settings. The majority of learning disability support has now transferred from health to social care and the funding and skills from these health settings must follow. Further strategic planning to increase the availability of nurse led social care and adequate social care funding is required to ensure these services are purchased.

*Responsibilities: Health and social care commissioning*

- **Social care nursing development**

Social care providers must commit to supporting nurse registration requirements, clinical governance, nursing leadership, and continuing professional development to embed their value for learning disability nurses in these settings. Local authorities must include in planning services for their locality to have social care that is led by learning disability nurses as part of their provider market requirements.

*Responsibilities: Social care providers*

- **Nursing student funding**

Government administrations must continue to effectively fund academic preparation to become a learning disability nurse. Apprenticeship schemes and enhanced bursary grants for student learning disability nurses in England are demonstrating that they can revive attraction to become a learning disability nurse, particularly for mature students, and they support health and social care providers to be able to offer career development opportunities to their employees.

*Responsibilities: Government administrations and educational institutions*

- **Nurse leadership development**

Leadership development must be urgently addressed in pre-registration training and as a post-registration requirement. This needs to be competency based to ensure that learning disability nurses are well equipped to lead positive cultures, advocate for people's human rights, and effectively challenge closed cultures that can grow abusive practices.

*Responsibilities: Employers and commissioners*

- **Hospital liaison standards**

Safe staffing standards should be set regarding how many learning disability liaison nurses are required in each acute hospital per 100,000 population. Standards should also be set relating to availability of these roles, level of experience required, leadership skills required, and governance and leadership arrangements for these roles.

*Responsibilities: Commissioning, acute hospital services*

- **Community support for challenging/offending needs**

There must be a review of statutory community supports for people with learning disabilities who present challenging behaviours and behaviours that may be considered an offence, such as intensive support teams and community forensic services. This is to ensure that availability in all areas is consistent and that they are fit for purpose. This is essential if aspirations to continue to reduce hospital admissions are to be realised.

*Responsibilities: Commissioning authorities, health and justice agencies, professional bodies*

- **Learning from deaths**

Commitment is required to ensure that learning disability mortality reviews continue to be undertaken and that learning occurs from these reviews on a local level. The policy for this in England has recently been updated to ensure this (NHS England, 2021), and we ask all four UK countries to ensure the same processes for learning from deaths is in place.

*Responsibilities: Health authorities*

- **Health inequalities**

Given the health inequalities that continue to be experienced by people with learning disabilities, annual health checks for people with learning disabilities should be reviewed to evaluate their uptake and their effectiveness. Not enough is being done to significantly address these health inequalities and this must change. A full review is called for in each of the four nations to identify quality of coverage and barriers to access.

*Responsibility: Health authorities*

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## RCN quality assurance

### Publication

This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

### Description

This publication explores contemporary issues concerning the field of learning disability nursing and sets out a series of recommendations and priorities that the UK government and devolved administrations must address. It also identifies priorities for the RCN to take forward.

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### The Nine Quality Standards

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