



ROYAL COLLEGE OF NURSING WALES

LEARNING DISABILITY NURSING



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RECOMMENDATIONS

- Health boards must ensure learning disability nursing is embedded in every aspect of care, including primary care, community care, secondary care and specialist care. To do this, significant investment is needed in pre- and post-registration learning disability nursing.
- Care must be available to be delivered in Welsh. NHS Wales must ensure the Welsh language field on the NHS Electronic Staff Record is mandatory and the Welsh Government must publish this data to ensure effective workforce planning and delivery of care in Welsh.
- The Welsh Government must seek to understand the impact of the COVID-19 pandemic on people with a learning disability and ensure any potential negative effects of the pandemic are mitigated and people with learning disability are considered in plans for 'living with Covid' and recovery.
- NHS Wales must ensure the learning disability educational framework for healthcare staff in Wales, developed by Improvement Cymru and University South Wales in memory of Paul Ridd, is fully and consistently implemented across the NHS.
- The Welsh Government must ensure there are enough learning disability nurses in Wales to provide support for people throughout their lifespan including: early years, child and adolescent services, adult services, older age and end of life care. This must include increasing pre- and post- registration learning disability nursing and post-registration nursing education.
- The Welsh Government must ensure every health board and trust in Wales has at least one learning disability consultant nurse. Health boards, higher education providers, social care and independent providers must also ensure they have a pathway for learning disability nurses to advance in their careers.
- NHS Wales and employers must facilitate time for nurses to study, Health Education and Improvement Wales must commission postregistration nursing education and universities must establish learning disability consultant nurse and advance practice nursing courses.
- The Welsh Government must ensure accurate information on out of area and out of country placements is collated and published.
 Independent and social care providers must invest in learning disability nursing to ensure care should be provided closer to home.





EXECUTIVE SUMMARY

A learning disability nurse provides specialist health care and support for people with a learning disability, their families and staff teams. Learning disability nurses are required wherever an individual with a learning disability has complex health care needs and requires specialist care and support. The learning disability nursing workforce should be celebrated and valued for their highly skilled, compassionate role.

The Royal Collage of Nursing (RCN) published a UK-wide report Connecting for Change: the future of learning disability nursing.¹ The report provided a four nation overview of the current challenges facing the workforce. This paper is complementary to the UK-wide report and will provide specific recommendations for the Welsh Government, NHS Wales and Health Education and Improvement Wales (HEIW).

¹ Royal College of Nursing, 2021, *Connecting for Change: the future of learning disability nursing*, available at: https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/publications/2021/june/009-467.pdf?la=en [Accessed 12 January 2022].

INTRODUCTION

What is a learning disability?

A learning disability as defined by the National Institute of Health and Care Excellence (NICE) generally encompasses three core components:

- Lower intellectual ability (usually an IQ of less than 70)
- Significant impairment of social or adaptive functioning
- Onset in childhood.

A learning disability can be mild, moderate, or severe and the level of assistance and support an individual needs is dependent on the severity of their learning disability and the individual. It is important to remember that people with milder learning disabilities most often live independently and care for themselves, manage everyday tasks, work in paid employment and communicate their needs and wishes. People with milder learning disability may have additional needs that are not clear to people who do not know them well.²

People with a more severe learning disability are more likely to need support with daily activities such as getting dressed, washing, food preparation and keeping themselves safe. They may need support with mobility and have complex health needs and sensory impairment.³

The United Nations Convention on the Rights of Persons with Disability, Article 25 states that people with disability have the "right to enjoy the highest attainable standard of health without discrimination on the basis of disability". Unfortunately, this is not always the case in reality. People with a learning disability face more enduring health inequalities compared with the general population and experience worse health outcomes. Learning disabilities can often be coupled with health conditions including, epilepsy, mental health problems and physical impairment and frequently multimorbidity is experienced leading to complex health needs.

People with a learning disability can face increased risk of preventable death.⁶ In 2018, the Learning Disabilities Mortality Review found the median age at death was 60 for a man with a learning disability and 59 for a woman.⁷ This is significantly less than the median age of death of 83 for a man and 86 for a woman in the general population; the difference being 23 years for men and 27 years for women. Whilst this review was focused on England it is reasonable to assume these statistics will equally apply to Welsh citizens.

⁷ NHS England, *Learning Disability Mortality Review (LeDeR) Programme: Action from Learning*, available at: https://www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning.pdf [Accessed 12 March 2022].





² NICE, *Learning disabilities Health topics A to Z*, available at: https://cks.nice.org.uk/topics/learning-disabilities/ [Accessed 12 March 2022].

³ NICE, *Learning disabilities Health topics A to Z*, available at: https://cks.nice.org.uk/topics/learning-disabilities/ [Accessed 12 March 2022].

⁴ United Nations, Article 25, available at: Article 25 - Health | United Nations Enable [Accessed 10 March 2022].

⁵ NICE, *Mental health problems in people with learning disability*, available at: https://www.nice.org.uk/guidance/ng54/documents/mental-health-problems-in-people-with-learning-disabilities-draft-scope2 [Accessed 9 March 2022].

⁶ Learning Disability Mortality Review Programme,2018, *Annual Report 2018* available at: http://www.bristol.ac.uk/sps/leder/resources/annual-reports/ [Accessed 10 March 2022].

Data on people with a learning disability throughout their life in Wales is poor: this has been recognised by the Welsh Government. To ensure Wales can meet the needs of those with a learning disability the Welsh Government first needs to understand how many people with a learning disability live in Wales and what their needs are.

Public Health Wales (PHW) has estimated that there are approximately 15,600 people with a learning disability who were either resident in Wales or registered with a GP in Wales on 29 February 2020.8 However, we know that not all people with learning disabilities are registered with a GP or known to social services. Mencap has estimated that there is between 54,000 to 60,000 people with a learning disability in Wales, including 16,000 children with a learning disability.9

What is a learning disability nurse?

Registered learning disability nurses work in one of the four fields of nursing and have a recognised point of entry to the Nursing Midwifery Council (NMC) register as a registered nurse.

Ten years ago the UK Governments published a report, Strengthening the Commitment The UK Modernising Learning Disabilities Nursing Review. The report detailed that there had been some debate about the relevance of learning disability nursing in the context of the shift to a social model of provision, but there was a recognition that learning disability nursing continues to play a crucial role in championing health improvement and working to tackle the health inequalities.¹⁰

The principles and guidance underpinning learning disability nursing are:

- human rights: valuing choice, inclusion, citizenship and social justice
- **personalisation:** support the individual's control and choice over their life and services
- equality and inclusion: recognising diversity and challenging inequality and inequity
- person-centred: engagement with people to identify goals significant to the person
- strength-based: focus on existing strengths, skills, talents and resources
- respect: value the person and the diversity of people who support and sustain themselves
- partnership: recognise that health and social outcomes are interdependent
- health-focused: focus on the individual's health and wellbeing to enable inclusive lifestyles. II

⁸ Public Health Wales, *COVID-19-related deaths in Wales amongst People with Learning Disabilities from 1st March to 19th November 2020*, available at: https://phw.nhs.wales/publications/publications1/covid-19-related-deaths-in-wales-amongst-people-with-learning-disabilities-from-1st-march-to-19th-november-2020/ [Accessed 14 March 2022]

⁹ Mencap, *Learning disability explained* available at: https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability [Accessed 12 March 2022].

¹⁰ Four nation Governments 2012, Strengthening the Commitment The Report of the Modernising Learning Disabilities Nursing Review, available at: https://gov.wales/sites/default/files/publications/2019-03/strengthening-the-commitment.pdf [Accessed 1 March 2022].

¹¹ Four nation Governments 2012, *Strengthening the Commitment The Report of the Modernising Learning Disabilities Nursing Review*, available at: https://gov.wales/sites/default/files/publications/2019-03/strengthening-the-committment.pdf [Accessed 1 March 2022].

"The learning disability nurse has always had a unique place in the lives of people with a learning disability and their families.

They connect individuals, their family/carers and support staff to the NHS, which we know can be a daunting prospect for many.

Learning disability nurses are there to place people at the centre of the health care they receive and to empower them to take ownership over their health needs.

Their role is a recognition that social and health outcomes are connected, and that the wellbeing support people receive needs to be brought to individuals, not the other way round

The role of the learning disability nurse needs to be enhanced, to support people to access mainstream health services.

Mencap Cymru would welcome investments in the role of Learning Disability Liaison Nurses in Acute Hospital settings".

Wayne Crocker, Director Mencap Cymru

A learning disability nurse provides specialist health care and support for people with a learning disability, their families and staff teams. Many people with learning disabilities experience longterm conditions, with 46% of people experiencing more long-term conditions. seven or Approximately 98% of people with a learning disability have been prescribed medication, and the average number of medications a person with learning disabilities is prescribed is 6.2.12 Identifying and treating the health needs of a person with a learning disability can be complicated by communication difficulties, unusual presentations of symptoms, and diagnostic overshadowing. This highlights the importance of learning disability nurses in providing health care and reducing health inequalities by having a person-centred approach.

Learning disability nurses require an in-depth knowledge of rights-based legislation (and conventions), the Mental Capacity Act (2005), the Mental Health Act (1983) and the Mental Health (Wales) Measure (2010). This involves recognition that some people with a learning disability who require health care can experience care as coercive and learning disability nurses have legal duties in this context. The current NMC competencies state that registered nurses need to act in a manner which minimises the power imbalance between the nurse and service user in the unique context of compulsory care.¹³

Learning disability nurses may work within environments such as secure units and criminal justice organisations where there is an immediate imbalance of power which can leave some of our most vulnerable citizens open to abuse, for example, Winterbourne, 2011¹⁴. It is essential that people with a learning disability who need specialist nursing services can access them and be assured that those delivering their care are registered competent practitioners.

¹⁴ BBC News, 2012, Timeline: *Winterbourne View abuse scandal*, available at https://www.bbc.co.uk/news/uk-england-bristol-20078999 [Accessed 5 March 2022].





¹² Learning Disability Mortality Review programme, 2020, *Annual Report 2020*, available at: LeDeR programme annual report 13.05.2021 FINAL.pdf (bristol.ac.uk) [Accessed 2 March 2022].

¹³ Nursing and Midwifery Council, 2018, *Standard for Competence for Registered Nurses*, available at: https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-competence-for-registered-nurses.pdf [Accessed 15 March 2022].

A key and essential role of the learning disability nurse is in the provision of care and interventions that promote, sustain, and maintain, biological, psychological and social wellbeing. In line with public health policy, the learning disability nurse focuses on early intervention and systemic health improvement approaches.¹⁵

¹⁵ Royal College of Nursing Northern Ireland, *The Registered Nurse - Learning Disability*, available at https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/news/2018/rcn-northern-ireland-learning-disability-nursing-network-gui dance.pdf#:~:text=The%20Registered%20Nurse%20-%20Learning%20Disability%20supports%20the,Professionalism%20and%20the%20Registered%20Nurse%20-%20Learning%20Disability [Accessed 12 March 2022].

Section 1: Learning Disability Services

SECTION 1

Learning Disability Services

A learning disability is a lifelong condition and services are often needed throughout an individual's life. Importantly, services need to be provided based on the individual's needs and should be available in Welsh as well as English. Learning disability nurses make a key contribution to quality nursing service delivery across the lifespan of an individual. This includes contact and interventions with babies and children, during school years, at transition to and throughout adulthood and, increasingly, in the later years to end of life. The skills and competencies of learning disability nurses must be available at every key life stage.

Early years

There are currently 16,000 children with a learning disability in Wales.¹⁶

Some learning disabilities are diagnosed at birth, whilst others are not identified until much later. The impact of a child's learning disability will become clearer as they grow and develop, e.g. talking, walking or reading. For children who are not diagnosed at birth, obtaining a diagnosis of a learning disability can be a lengthy process because learning disabilities are quite hard to diagnose very early in life.¹⁷ A learning disability nurse will be able to assess and address the impact of a child's disability to support their development, wellbeing and quality of life.

A child with a learning disability is more likely to face challenges with physical and mental health, family poverty and difficulty at school. Support during the early years will boost early development and provide children with the best start to life.

The North Wales Learning disability strategy 2018–2023 noted that family-focused support is available in some areas from Flying Start and across North Wales from Families First and Team Around the Family, known as Together Achieving Change in Wrexham.¹⁸

Early years support is provided by specialists and services such as: musical interaction therapy, play therapy, hydrotherapy, physiotherapy, early intervention programmes, child development centres, preschool development and school age learning disability teams. These services provide the best start for a child with a learning disability whilst also providing support for the family in a safe environment.

¹⁸ North Wales Social Services and Wellbeing Service Improvement Collaborative, 2018, *North Wales Learning Disability Strategy 2018 to 2023*, https://www.northwalescollaborative.wales/wp-content/uploads/2019/04/NW-Learning-Disability-Strategy-2018-FINAL-1.0-2.pdf [Accessed 3 March 2022].





¹⁶ Mencap, 2019, *How common is learning disability?*, available at https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability. [Accessed 28 February 2022].

 $^{^{17}}$ Dr Martin Ward Platt, consultant paediatrician at Royal Victoria Infirmary, Newcastle-upon-Tyne, available at

However, despite these initiatives families continue to face barriers in finding the help they need. Mencap reported that families have told them they experience difficulties in:

- finding out what their child's needs are once they suspect a problem
- finding good quality information about their child's needs and opportunities to develop and access support
- finding good quality support to meet their needs and the needs of their child in the early years
- finding professionals who have the right skills and attitudes to work well together to meet their child's additional needs.¹⁹

Early year services are imperative to ensuring every child has a successful start to life and their family members feel supported. Health boards must evaluate what services they provide and ensure they are following a 'no wrong door' approach.²⁰ Children and young people with a learning disability, their families and carers, too often, still face complicated and stressful experiences navigating through services. The 'no wrong door' approach prevents individuals being 'bounced' between services who cannot agree who is best placed to provide care for the individual. The Children's Commissioner describes the 'no wrong door' as a wrap-around approach which see the individual, their families, and carers at the centre of care and expresses that it is not the responsibility of the individuals or their families to navigate complex systems. There is a need for health boards to invest in health services for children with a learning disability.

To support children with a learning disability and their families it is important that learning disability nurses are able to work alongside midwives, health visitors, school nurses, community nursing teams, paediatric wards and child and adolescent learning disability services, child and adolescent mental health services and palliative care.

This must include an overall investment in learning disability nursing from every health board. Health boards should give specific and conscious attention to ensuring the health needs of children and young people with learning disabilities are appropriately prioritised and addressed. The skills, knowledge and expertise of learning disability nurses must be maximised to ensure high-quality services and interventions for children with learning disabilities and their families. A 'no wrong door' approach would ensure services are wrapped around the individual and their family rather than asking them to navigate a very complex system. The numbers of 'special schools' have been reduced in Wales with an expectation that children with a learning disability are integrated into mainstream schooling. For most, this can be beneficial for the child and the community, but some children require a specialist environment to provide them with opportunities to learn and thrive and meet their complex accompanying health needs.

¹⁹ Mencap, *Early Years What we think*, available at: https://www.mencap.org.uk/about-us/what-we-think/early-years-what-we-think [Accessed 3 March 2022].

²⁰ Children's Commissioner for Wales, *No Wrong Door: bringing services together to meet children's needs*, available at: No Wrong Door: bringing services together to meet children's needs - Children's Commissioner for Wales (childcomwales.org.uk) [Accessed 7 March 2022].

Section 1: Learning Disability Services

ACTION

Health boards must ensure learning disability nurses are embedded in every aspect of care, including primary care, community care, specialist care and secondary care. The health boards must take a no wrong door approach and ensure services are wrapped around the individual and their families. To do this, significant investment is needed in pre-and-post registration learning disability nursing.

Child and adolescent services

In Aneurin Bevan and Betsi Cadwaladr University health boards there are specialist Child and Adolescent Learning Disability Services (CALDS). These services are run in parallel with Child and Adolescent Mental Health Services (CAMHS) to offer specialist support for child and adolescents aged 4-18 (Aneurin Bevan) and 5-18 (Betsi Cadwaladr).²¹ These services are run as part of the Healthier Together and North Wales Together initiatives.

CALDS are offered to children who have a moderate to severe learning disability that is associated with behaviours that challenge or complicate their mental health. The multidisciplinary team provides a joint assessment with CAMHS and supports the individual through their transition from child to adult.

Child and adolescent services are crucial in supporting an individual's transition into adult services.

Transition from child to adult

Getting the transition from child to adult services right is critical, especially for those who have a learning disability and complex health needs. However, there is very little information on how a child with a learning disability should transition to adult services and who can help them do so.

In January 2020 the previous Welsh Government (2016-2021) published a consultation on guidance on how to help children and young people navigate through the healthcare system. The guidance was published in February 2022 under the current Welsh Government.²² The guidance does not explicitly mention the challenges an individual with a learning disability would experience transiting from child to adult service or the impact a learning disability nurse would have on their transition.

Transition from child to adult services is a complex system and can be extremely difficult to navigate. For every child transitioning from child to adult services this should begin at the age of 14 and continue until the individual is 25 years old. This would allow for a comprehensive assessment and transition. For a child with a learning disability who needs health care and support in adulthood, learning disability nurses need to be able to support their transition.

²² Welsh Government, 2022, *Transition and over from children's to adult health services*, available at: The Transition and Handover Guidance_February 2022 (gov.wales). [Accessed 1 March 2022].





²¹ Child and Adolescent Learning Disability Services: Healthier Together (cymru.nhs.uk).

Older people

People with a learning disability are living longer and with this they are more likely to develop health conditions associated with older age. Comorbidity of illnesses is on the rise within the general population due to people living longer. The rise of comorbidity is also present and more prevalent from an earlier age in those who have a learning disability. This makes caring for older people with a learning disability increasingly complex. People with a learning disability, particularly those with Down Syndrome, are at an increased risk of developing dementia.²³

From the limited data gathered by Stats Wales it is clear that more older people (65+) identified as having a learning disability are living in their own home, with family or supported living than they did 10 years ago. In 2008-2009, 195 people were registered as living in their own home, this has risen to 223. ²⁴ Those living with their parent or family rose from 90 to 167 and the biggest rise is for supported living, increasing from 252 to 347. ²⁵ The trend of older people who have a learning disability living in their own home or family home is mirrored by a subsequent fall in the number of people with a learning disability registered in health service and local authority accommodation.

Caring for an older people has become a specialist field in itself as people are living longer, with more complex needs and high comorbidity. In addition people with a learning disability tend to develop age-related illnesses younger in life and this may require 'older person' health care at a younger age.

Alzheimer's UK have noted that people with a learning disability will often show different symptoms in the early stages of dementia, are less likely to receive a correct or early diagnosis of dementia and may experience a more rapid progression of dementia and may not understand the diagnosis. The individual will need specific support to understand the changes they experience and access to appropriate services after diagnosis. It is crucial that not only does the individual have access to appropriate services but also learning disability nurses and those educated in learning disabilities for older people.

The rise in comorbidity of illnesses associated with older age means that an individual with a learning disability may experience health conditions that will require attention, support and advice from a health professional. Heart disease and malignant neoplasm of trachea, bronchus and lung remain two

²³ Alzheimer's Society, UK *What is different about dementia in someone with a learning disability?* available at: What is different about dementia in someone with a learning disability? | Alzheimer's Society (alzheimers.org.uk) [Accessed 18 March 2022].

²⁴ Stats Wales, 2020, Persons with learning disabilities by local authority, service and age range, available at https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Disability-Registers/personswithlearningdisabilities-by-localauthority-service-agerange [Accessed 14 March 2022].

²⁵ Stats Wales, 2020, Persons with learning disabilities by local authority, service and age range, available at https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Disability-Registers/personswithlearningdisabilities-by-localauthority-service-agerange [Accessed 14 March 2022].

²⁶ Alzheimer's Society, UK *What is different about dementia in someone with a learning disability?* available at: What is different about dementia in someone with a learning disability? | Alzheimer's Society (alzheimers.org.uk) [Accessed 18 March 2022].

Section 1: Learning Disability Services

"Supporting people to achieve things they previously had not. Recently I supported a gentleman in his late 40s to make his toast in the morning; he later told me it was the first time he'd ever made his own breakfast and was super proud."

LD Nurse, RCN Wales Member of the leading cause of death for those aged 65 to 79.²⁷ Both of these illnesses are long term conditions and would require support and assistance. It is important that any care of an individual with a learning disability is provided in consultation with a learning disability nurse to provide the necessary support for the individual to understand their changing health.

An aspect which is often not thought about in relation to older people with a learning disability is falls that require health care. Falls for the older population are more common than the younger population, and for those with a learning disability it is even more so. A recent study by Axmon et al. (2018) found that individuals with a learning disability were more likely to be prescribed fall-risk increasing drugs (FRIDs) than the general older population. FRIDs include antipsychotics, anxiolytics, antidepressants and hypnotics and sedatives. However, the study found that with or without prescriptions of FRIDs, older people with a learning disability were at a higher risk of falls requiring health care than older people in the general population. It is also important to recognise the contribution that learning disability nurses can make, in terms of assessment, prevention, and responding to falls, when considering the additional complexities that may arise when a person with learning disabilities is at risk of multiple health problems.

Learning disability nurses promote healthy ageing and have an important role in health promotion and prevention. Commissioners and providers of health and social care should ensure the skills, knowledge and expertise of learning disabilities nurses are available across the lifespan. This should be enabled through effective collaborative working across health and social care.

It is also important that commissioners and providers of health care are mindful that life expectancy for an individual with a learning disability may not be the same as the general population and an individual with a learning disability may require 'older persons care' at a younger age. Learning disability nurses play a key role in the planning and provision of services that are equitable and safe.

Welsh language

The Welsh language is an important aspect of Welsh identity and is a right in law.

Not all healthcare staff will have the tools and skills needed to communicate with an individual who has a learning disability. An individual with a learning disability may not be able to interpret their environment as easily as others and may struggle with medical language. If an individual is unable to communicate in their preferred language this introduces a further barrier. Having access to Welsh speaking carers, healthcare and support staff is crucial for creating an environment that enables an individual with a learning disability to feel comfortable communicating.

²⁷ Office of National Statistics, 2020, *Leading causes of death UK*, available at: Leading causes of death, UK - Office for National Statistics (ons.gov.uk) [Accessed 14 March 2022].





An individual with a learning disability needs to be able to communicate in their desired language whenever they come into contact with health or care staff; this includes assessment and treatment.

The NHS 'Active Offer' means services should be provided in Welsh without someone having to ask for it.²⁸ The Welsh language should be as visible as the English language. To do this there needs to be a workforce in place to provide Welsh speaking services.

Nearly a third (29.5%) of the population in Wales can speak Welsh.²⁹ In the RCN Employment Survey 2021, 35.7% of Welsh respondents indicated that they could speak Welsh. However there is no public information on the percentage of Welsh speakers in the health and social care workforce.

The Electronic Staff Record (ESR) is a tool used by England and Wales to gather workforce intelligence. The ESR records the NHS workforce's ability to speak Welsh; however, there is no mandatory field to fill out regarding fluency in the Welsh language and this means information can be inconsistent. To ensure information is accurate any field regarding the ability to communicate in Welsh must be standardised and mandatory to complete.

By gathering up-to-date accurate information, this will allow the Welsh Government, NHS Wales and employers to understand the demographics of the workforce and consequently seek to meet the needs of the population through ensuring a bilingual workforce is available.

If there are too few Welsh speakers or there are Welsh speakers who do not feel confident speaking Welsh in a clinical setting then the Welsh Government, HEIW and NHS Wales can begin to address this by providing educational opportunities in Welsh for the current workforce or provide more pre-registration education in Welsh.

ACTION

Health boards must ensure learning disability nurses are embedded in every aspect of care, including primary care, community care, specialist care and secondary care. The health boards must take a no wrong door approach and ensure services are wrapped around the individual and their families. To do this, significant investment is needed in pre-and-post registration learning disability nursing.

Welsh Government, 2019, More than just words Delivering the Active Offer Information Pack, available at: Active offer information pack part 1 English (gov.wales) [Accessed 15 March 2022]

²⁹ StatsWales, 2022, Annual Population Survey - Ability to speak Welsh by local authority and year, available at: https://statswales.gov.wales/Catalogue/Welsh-Language/Annual-Population-Survey-Welsh-Language/annualpopulationsurveyestimatesofpersonsaged3andov erwhosaytheycanspeakwelsh-by-localauthority-measure [Accessed 13 March 2022].

SECTION 2

COVID-19

The COVID-19 pandemic has had an unprecedent impact on all areas of society, but it has become well known that the pandemic has had an unequal impact on pockets of society including people with learning disabilities. The pandemic has exposed high levels of health inequalities within our society. People with learning disabilities already experienced more health inequalities than the general population, demonstrated by the increased rate of premature and preventable deaths, and COVID-19 has sadly highlighted this.

A report by PHW noted COVID-19 deaths are three to six times higher in those with a learning disability than the general population in Wales.³⁰ The higher death rate mirrors the higher non-COVID-19 mortality rate experienced by those with learning disabilities.

Many people with a learning disability felt isolated, anxious and left behind during the COVID-19 pandemic. There were difficulties regarding shielding; whether an individual should be shielding; understanding the Welsh Government or GP letter and trying to remain safe whilst relying on physical interaction due to their care needs. Furthermore, restrictions that were put in place for the general population were not always suitable for those with learning disabilities. For example, in evidence to the Fifth Senedd Health, Social Care and Sport Committee the Learning Disability Consortium detailed that there was confusion and anxiety regarding the term 'social' distance, challenges and fears relating to public transport, one-way systems in stores and online shopping.³¹ Access to respite services, day services and support groups were significantly reduced and, on some occasions, totally withdrawn.

Anecdotally there has also been a huge impact on children with learning disability. School closures, closure of day services and support groups, less face to face support, online appointments and insufficient technology in the home to support access all had an impact on children with a learning disability and their families.

The experience of those with a learning disability during the COVID-19 pandemic has not yet been fully understood, but there is ongoing research. The first findings of a UK study on the impact of the COVID-19 pandemic on people with a learning disability found:

- About half of respondents with a learning disability had a health condition that made them or their carers worry about a coronavirus infection
- More than 60% of respondents with a learning disability who had routinely seen health care professionals before the first lockdown in March 2020 had seen them less or not at all since then
- 80% of respondents with a learning disability were concerned about their family or friends catching COVID-19. This was a larger percentage than the people who were worried about catching it themselves (66%).³²

The research has focused specifically on people with learning disabilities, who may have found it difficult to take part in other studies of the pandemic's impact or whose voices may not have been heard.

ACTION

The Welsh Government must seek to understand the impact of the COVID-19 pandemic on people with a learning disability and ensure any potential negative effects of the pandemic are mitigated and people with learning disability are considered in plans for 'living with Covid' and recovery.

³² University of South Wales, 2022, *Research highlights COVID-19 challenges faced by people with learning disabilities*, available at: Research highlights COVID-19 challenges faced by people with learning disabilities | University of South Wales [Accessed 10 March 2022].





³⁰ Public Health Wales, 2021 *New report confirms people with learning disabilities at increased risk of death from coronavirus*, available at: https://phw.nhs.wales/news/new-report-confirms-people-with-learning-disabilities-at-increased-risk-of-death-from-coronavirus/ [Accessed 11 March 2022].

³¹ Learning Disability Consortium, 2020, *Health, Social Care and Sport Committee evidence*, available at: https://business.senedd.wales/documents/s103006/C60%20-%20Learning%20Disability%20Consortium.pdf [Accessed 7 February 2022].

From a nursing perspective:

Why learning disability nursing is so important

LD Nurse. RCN Wales Member

Why did you choose learning disability nursing?

"Even as a child I wanted to know more about people who were presented as different and ignored by others. My mum tells stories about how I always wanted to speak to people I met, those in wheelchairs or sitting away from others, signing or talking differently to me. I have many stories of the times I would ask those questions others would not ask and fight against those opinions of others. I feel I always wanted to make a difference and help them [people with a learning disability] find their voice".

What is the most rewarding part of your job?

"Making a difference, however small, in someone's life makes the job worthwhile, taking the time to listen and try and work through the difficulties. Helping them find a voice or supporting them to do the things they want in life".

What is the most challenging part of your job?

"The inability to sometimes have the answers or the resources they [people with a learning disability] need to progress in life. Even now society is still very difficult in many respects".

If the Welsh Government could do one thing to improve your role, what would it be?

"Have more understanding of the role we have and how difficult it can be when we are not recognised or appreciated in the same way as general and mental health nurses. Look at the current provisions as there are not enough specialist services around and our patient group are still the forgotten ones. So many times, I have heard the snub, 'You are not a real nurse' which I suppose makes me guestion 'What is a real nurse?'"

What one piece of advice would you give someone thinking of becoming a learning disability nurse?

"It is not an easy job if you go into it for the right reasons. Your patients often become as close as family and the worry and concern you have for them never turns off whilst they are in your care. But when you achieve even the smallest of breakthroughs it feels absolutely amazing."

SECTION 3

Workforce

Having discussed the importance of learning disability services from early age to older age, it is essential that there is a workforce able to provide these services and deliver the right level of support for people with a learning disability.

Learning disability nurses are not solely responsible for caring for an individual with a learning disability, but they do provide specialist knowledge and expertise as expressed in the introduction, that is invaluable when providing care and support for an individual with a learning disability. They also facilitate acts of coordination of care and support services.

This section outlines the needs of the general workforce and the requirement for the necessary expansion of the pre-registration nursing workforce and urgent investment in specialist, advance practice, and consultant nurses.

General workforce

People with a learning disability use health and social care services in the same way as people without a learning disability. It is important that sufficient learning disability nurses are available to care for these individuals and also that the general workforce understands the complexities of providing care for someone with a learning disability and their responsibilities in relation to providing such care.

The general workforce, whether in primary, community, secondary or social care, will encounter and care for people who have a learning disability. It is important that in doing so, the workforce understands how to make reasonable adjustments under the Equality Act 2010 and care for someone with a learning disability to ensure the individual's learning disability does not overshadow their additional health needs or prevent access to services to meet these needs.

A pivotal way for ensuring the general workforce are aware of the needs of people with a learning disability is to provide educational opportunities for them to develop their understanding. This includes implementing the Improvement Cymru Education Framework for healthcare staff, in memory of Paul Ridd.

The Framework was developed in memory of Paul Ridd³³, following a successful petition by the Paul Ridd Foundation to establish mandatory training for health care staff on learning disabilities.³⁴ The University of South Wales was commissioned by Improvement Cymru to devise an education framework for healthcare staff as part of the Learning Disability Improving Lives Programme.³⁵ Improvement Cymru are taking forward the implementation.

³³ Paul Ridd Foundation, About Paul, Available at https://paulriddfoundation.org/pauls-story/,

³⁴ BBC Wales News, Paul Ridd Foundation petition prompts debate over health inequalities, Available at https://www.bbc.co.uk/news/uk-wales-50304722,

³⁵ Improvement Cymru, 2021, *Learning disability educational framework for healthcare staff in Wales*, available at: https://phw.nhs.wales/services-and-teams/improvement-cymru/news-and-blog/publications/learning-disability-educational-framework/ [Accessed 14 March 2022].

Within the Framework there are three tiers of competence:

- Foundation the values, knowledge and skills required of all health care staff
- **Enhanced** the values, knowledge and skills required of those health care staff whose role brings them into regular contact with people with learning disabilities.
- Advanced the values, knowledge and skills required of those health care professionals who work in specialised clinical areas that involve working with people with learning disabilities with associated health care needs, e.g. epilepsy, dysphasia, neurodevelopment disorders.

It should be stressed that the foundation tier is applied to all staff in health care settings, this includes receptionists, administrative staff, porters, managers and board members.

The Framework provides details of the varying levels of knowledge and skills in each tier people would be expected to achieve in numerous areas, including understanding learning disabilities, removing barriers, caring for the health needs of an individual with learning disabilities, responding to behaviour, coordination and collaboration and legal and policy issues.

For example, an individual at a foundation tier should understand that all behaviour has meaning, and that behaviour is a means of communication. An individual on the enhanced tier would have an understanding of the basic principles of positive behaviour support. An individual at the advanced tier would have the values, knowledge and skills required to provide specialist health care for a person with a learning disability.

Registered learning disability nurses are beyond the advanced tier as they have a recognised, recordable qualification that equips them to provide care within all health and social care settings. Learning disability nurses often work with people who have profound and multiple disabilities which may include both physical and mental health problems. These specialist skills and knowledge allow them to provide care and interventions that promote, sustain, and maintain, biological, psychological and social wellbeing.

Learning disability nurses can take responsible for educating others and have a role in implementing the framework and supporting the development and understanding of the general workforce.

The Framework provides a simplistic and yet detailed analysis of the values, knowledge and skills that are required of the general workforce to provide care and support for those with a learning disability. It is essential that everyone working in a health care setting is familiar with the requirements of the foundation tier. It is also imperative that those who interact regularly with people with a learning disability are either at an enhanced or advanced tier. The Framework will reduce the risk of diagnostic overshadowing. Diagnostic overshadowing is when an individual's health illness and symptoms are overshadowed by their learning disability.

ACTION

NHS Wales must ensure the 'learning disability educational framework for healthcare staff in Wales' developed in memory of Paul Ridd, by Improvement Cymru and University South Wales, is fully and consistently implemented across the NHS.

Learning disability workforce

"Learning disability nursing works wherever in the community people with learning disability access health care. We're not just providing learning disability care as services with inpatients, we work across liaison nurses, children nurses, GP surgeries: we work everywhere. I am really concerned that the numbers of recruitment that they have for the universities doesn't reflect this."

(RCN Wales Member, LD Nurse)

The learning disability nursing workforce is essential for ensuring a person with a learning disability is cared for with dignity and provided with expert clinical care that is evidence based, compassionate and person centred. Learning disability nursing is not confined to one area.

It is important that there are enough learning disability nurses, with a variety of skill mix, to meet the needs of people who have a learning disability. This must start with commissioning more pre-registration education places, but it must also continue with a career pathway and access to postregistration education to encourage nurses to become consultant nurse and specialists. advance learning disability nurses and academics. The RCN UK-wide work on professional frameworks and the work from Connecting for Change about developing a suite of competency standards for the profession should be considered and developed for the nursing workforce in Wales.

Pre-registration learning disability education

Pre-registration nursing education prepares students for degree level registration in one of four fields of nursing practice: adult, child, mental health and learning disability. The Welsh Government has increased pre-registration nursing education and RCN Wales welcomes this, but there is a clear lack of investment in mental health, children and learning disability nursing.

The number of places commissioned for learning disability nursing was static at 77, between 2018 to 2021. The number rose slightly to 86 for 2022-2023.

Despite the extremely low commissioned number HEIW reported that Welsh "education providers were unable to recruit to the commissioned education levels previously agreed".³⁶ There needs to be more of an emphasis on making the role of a learning disability nurse visible and seen as an attractive career for younger people. HEIW's Careersville³⁷ is a positive step in demonstrating the importance of learning disability nursing but more is needed to be done to attract people to the profession.

³⁷ Health Education and Improvement Wales, *Careersville*, available at: https://careersville.heiw.wales/nursing [Accessed 14 March 2022].





³⁶ Health Education and Improvement Wales, 2020, *NHS Wales Education Commissioning and Training Plan for 2021/22.*

What is the most rewarding part of your job?

"Working hands-on with patients. Seeing patients admitted ill and the difference in their presentation when well and discharged. Seeing improvement in patients when rehabilitated and the impact on improving their quality of life. Advocating for the rights of people with a learning disability particularly in a general hospital setting to receive reasonable adjustments to ensure they receive good quality care."

(RCN Wales Member, LD Nurse)

This should include expanding access to the profession through part-time education and postgraduate level entry and increasing nursing student placements in social care.

Furthermore, despite HEIW stating universities were unable to fill the commissioned places, there is no data to further understand how many places are filled every year. There needs to be an improvement in data gathering and transparency of the number of places universities fill. This will provide a more accurate understanding of what the future workforce might look like

ACTION

The Welsh Government must ensure there are enough learning disability nurses in Wales to provide support for people throughout their lifespan including early years, child to adult services, older age and end of life care. This must include increasing preregistration learning disability nursing and post-registration nursing education.

Consultant nurse

Consultant nurses have an extremely senior role and are educated to MSc or PhD level. The role of a consultant nurse is one of the highest levels of nursing a registered nurse can achieve.

There are four main aspects to a consultant nurse's role:

- **1 Expert clinical practice** (*direct and indirect practice*). Working directly with individuals, families and carers, whilst indirectly influencing clinical work through supervising and providing guidance to others, developing practice protocols and exploring practice issues.
- **2 Professional leadership and consultancy.** Providing professional leadership and direct evidence based, client-centred recommendations to those involved in service development and delivery.

"The Paul Ridd Foundation was set up to support people with a learning disability, to access healthcare safely and equitably. Acute learning disability liaison nurses fulfil this role every day. Their work means that the experience of a patient will be more positive and less fearful, and time spent in hospital is reduced by 45%. They ensure that there is a safe discharge from hospital too, which means so much to families, and keeps patients safe.

We were promised 10 years ago that every health board would have a consultant learning disability nurse. There is still only one. We need people at this level to ensure improvements are made and areas of concern are addressed.

Patients with a learning disability should be able to access these experts at all levels in community, primary and secondary care. There is a real need to train more learning disability nurses as there is a growing population of people with a learning disability in Wales, and with the role out of the Paul Ridd Learning Disability Awareness Training commencing in April 2022, the need for additional specialist nurses to deliver this training is vital.

Learning disability nurses have exceptional skills, they enhance and ensure longevity of life for people with a learning disability. We as a Foundation can't stress enough the importance of job opportunities and real career progression for people in this profession".

(Jonathan, Jayne and Bridget at the Paul Ridd Foundation)

3 Education, training and development. Facilitate other
clinicians to develop their roles, gain
knowledge and skills either by
strategic planning education
initiatives, advising on higher
education routes or promoting
positive learning and clinical
settings.

4 Practice service development, research and evaluation. Develop evidence based protocols, research and explore implications of research upon service delivery.

In 2005, the then national body. Health Professions Wales, assessed the need for consultant nurses in Wales and approved the need for 55 consultant nurses and therapists posts for Wales. RCN Wales welcomes the increase of consultant nurses in recent years, as demonstrated by Figure 1, but it's been 16 years since the demand was made clear by Health Professions Wales and Wales still falls short of the recommendations by 13.6 consultant nurses.38

Despite the recent increase in consultant nurses, there is a clear lack of investment in learning disability consultant nurses as demonstrated by Figure 1. In 13 years, the number of learning disability consultant nurses has never risen above two and since 2016 the number of learning disability consultant nurses has remained static at one

There is a desperate need to improve the number of learning disability consultant nurses.

³⁸ StatsWales, 2022, Nursing, Midwifery and Health Visiting Staff by grade and area of work, available at: https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Staff/Non-Medical-Staff/nursingmidwiferyandhealthvisitingstaff-by-grade-areaofwork-year [Accessed 16 February 2022]





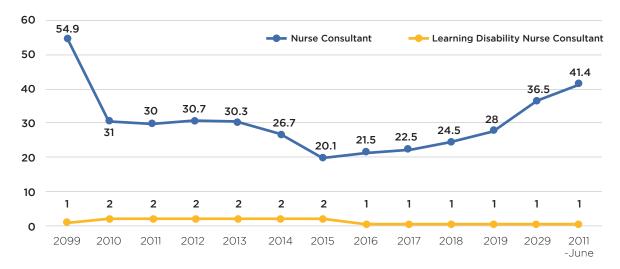


Figure 1: Number of WTE consultant nurses and learning disability consultant nurses (2009-2021)

Investing in learning disability consultant nurses would ensure Wales has the resources available to provide expert leadership; it would also ensure that Wales has the resources available to educate the next generation of learning disability nurses. It would improve the knowledge of the general workforce and produce innovative research, service improvement and development and function at a strategic level. To invest in learning disability consultant nurses is to invest in the whole system and embed the importance of individuals with learning disabilities rightfully at the centre of health and social care.

ACTION

The Welsh Government must ensure every health board and trust in Wales has at least one learning disability consultant nurse. Health boards must also ensure they have a pathway for learning disability nurses to progress in their careers.

Why is there a shortage of advanced, specialist and consultant nurse?

Wales does not have enough advanced and specialist nurses and consultant nurses. Although this shortage is not specific to learning disability nurses, it is extremely relevant within the field. This is due to the lack of post-registration opportunities. To ensure registered nurses are able to progress within their careers there needs to be a coherent, consistent career pathway to allow them to do so; this must include breaking the cycle of specialist nurse shortage.

When discussing the shortage of specialist nurses, especially in the field of learning disabilities, it is important to remember that Wales is not commissioning enough pre-registration learning disability nurses to meet current demand. Figure 2 illustrates why there is a cycle of shortages of specialist nurses.



NHS Wales cannot release nurses for study (backfill costs money)



Patients suffer lack of specialist nursing

HEIW is unable to commission postgraduate nurse education (no point as NHS does not want it)



Universities close departments in Wales, meaning no advanced nursing courses available in Wales, increasing costs of study and travel



Figure 2: The cycle of specialist nurse shortages

"Many of us get frustrated at our career prospects; there only seems to be management progression prospects for us. We would like some opportunities to be specialists [and] consultant nurses."

RCN Wales Member, LD Nurse Figure 2 highlights that NHS Wales, trusts and employers do not want to release nurses to study as there are already not enough nurses to backfill their post and it would also be very costly. This in turn means HEIW does not commission postgraduate nurse education as there are not enough nurses to fill the courses. Universities then close departments and withdraw advanced nurse education courses. As a result, any nurses able to study now have to travel further away, a time consuming and costly burden, and as many of these individuals have existing commitments, this acts as a deterrent from studying. Consequently, patients suffer as Wales does not have the specialist knowledge needed to provide the clinically advanced care, education, and research. This is especially true for learning disability advance practice, specialist, and consultant nurses.

To break the cycle, NHS Wales and employers must facilitate time for nurses to study, HEIW must commission post-registration nursing education and universities must establish learning disability consultant nurse and advance nursing Masters and PhD level courses in their area of practice.

ACTION

NHS Wales and employers must facilitate time for nurses to study, HEIW must commission post-registration nursing education and universities must establish learning disability consultant nurse and advance nursing courses.



From a nursing perspective:

Why learning disability nursing is so important

I D Nurse RCN Wales Member

Why did you choose learning disability nursing?

"I had just returned from America doing a summer of 'camp' with adults with physical and learning disabilities. I came home and knew I wanted a career in a similar field OR to go into nursing. When I googled USW [University of South Wales] and found there was such a thing as learning disability nursing I didn't hesitate to apply."

What is the most rewarding part of your job?

"Supporting people to achieve things they previously had not. Recently I supported a gentleman in his late 40s to make his toast in the morning; he later told me it was the first time he'd ever made his own breakfast and was super proud "

What is the most challenging part of your job?

"The lack of staffing, funding and resources."

If the Welsh Government could do one thing to improve your role, what would it be?

"Increase the pay for nurses. It is so much responsibility, legally, morally and professionally. Not to disrespect any other profession or job but I have known people working in less stressful environments, with less responsibility, earn more money than I do as a band 6 clinical lead in the NHS."

What one piece of advice would you give someone thinking of becoming a <u>learning disability</u> nurse?

"You would probably be financially better off seeking another line of employment. It is a very rewarding and heart-warming job but you need to be particularly resilient and look after your mental wellbeing."

SECTION 4

Independent Sector

Learning disability nurses work in a diverse range of settings, including assessment and treatment services, community teams, the independent sector, the criminal justice system and the education sector. Learning disability nurses provide generalist and specialist nursing care and work within geographically dispersed, inter-disciplinary and interagency community-based models. Some have strong links or are located within primary, secondary, mental health or acute services. Learning disability nurses work in a diverse range of settings as they are present wherever an individual with a learning disability needs support or health care.

The independent sector has increased its contribution to service delivery, becoming a major employer of learning disability nurses in the process, although the precise extent of those working in the independent sector is unknown.

Out of area placements

Out of area placements are very common for those needing residential support. Out of area placements can mean out of *county* and out of *country* placements and are often provided by local authorities and the independent sector.

Out of area placements can be challenging for the individual and their families. The full extent of out of area placements is unknown as the Welsh Government does not gather this information centrally.³⁹ Without central information of how many individuals are receiving out of area placements, the Welsh Government cannot fully understand how many people with a learning disability require complex care and how learning disability nurses should be commissioned.

In 2018, the Welsh Government published a report, *Learning Disability Improving Lives Programme*. The report recognised the strain out of area placements can have on families and the individual with a learning disability.

The report also commented about the abuse of people with a learning disability in Winterbourne View private hospital in England (2011) and the length of time taken for the Welsh Government to be informed that three Welsh people had previously been accommodated there. This raised the issue of out of county and out of country placements amongst other issues of overall safeguarding. It also highlighted the need to have data on the location of people with a learning disability, methods for monitoring out of country and out of country and whether lay people, e.g. families and carers, should be part of the inspection regimes.⁴⁰ Information should be held centrally by the Welsh Government on out of area placements and investment should be made to reduce the need for out of country/county placements. Care should be provided closer to home.

⁴⁰ Welsh Government, 2018, *Learning Disability Improving Lives Programme*, available at: https://gov.wales/sites/default/files/publications/2019-03/learning-disability-improving-lives-programme-june-2018.pdf [Accessed 1 March 2022].





³⁹ Welsh Government, 2021, *Out of area placements Freedom of Information Request*, available at: https://gov.wales/sites/default/files/publications/2021-09/ATISN%2015463.pdf [Accessed 16 March 2022].

ACTION

The Welsh Government should gather information on out of county and out of country placements. Independent and social care providers must invest in learning disability nursing to ensure care should be provided closer to home.

The title 'nurse'

In some cases, learning disabilities nurses are employed in social care or case manager roles. This can lead to the loss of recognition for their specialist nursing skills to the service and disadvantage those nurses wishing to progress within a recognised nursing career framework. It is important that learning disability nurses are recognisable as degree educated professionals with a unique skill set and expertise enabling the development and delivery of measurable, evidence based nursing care. Learning disability nursing is one of four specialist pathways through an undergraduate nursing degree, all of which lead to the title of 'registered nurse' and are regulated by the NMC. This means they are accountable to the NMC standards just like any other registrant and need to meet the revalidation requirements to ensure their practice remains competent. The title 'nurse' should be protected within learning disability nursing to ensure patient safety and public protection are properly assured as with other registered nursing roles.

Learning disability nurses who work in social care, whether in defined 'nursing' roles or not, have often been appointed due to their registered nurse status and the skills that this brings. There needs to be a recognition that the role of a learning disability nurse is essential, and employers should support nurses to complete their continued professional development, revalidation and supervision requirements.

CONCLUSION

Learning disability nursing continues to play a crucial role in championing health improvement and working to tackle health inequalities. This paper has outlined the necessity of learning disability nursing for providing healthcare and supporting an individual with a learning disability and their families.

From early years to older age, learning disability nurses should be able to provide care and support for a person with a learning disability and their family and carers. To do this there needs to be an expansion of pre-registration learning disability nursing, an expansion of career pathways and an investment in learning disability consultant nurses.

The Royal College of Nursing Wales recommends:

- Health boards must ensure learning disability nursing is embedded in every aspect of care, including primary care, community care, secondary care and specialist care. To do this, significant investment is needed in pre- and post-registration learning disability nursing.
- Care must be available to be delivered in Welsh. NHS Wales must ensure the Welsh language field on the NHS Electronic Staff Record is mandatory and the Welsh Government must publish this data to ensure effective workforce planning and delivery of care in Welsh.
- The Welsh Government must seek to understand the impact of the COVID-19 pandemic on people with a learning disability and ensure any potential negative effects of the pandemic are mitigated and people with learning disability are considered in plans for 'living with Covid' and recovery.
- NHS Wales must ensure the learning disability educational framework for healthcare staff in Wales, developed by Improvement Cymru and University South Wales in memory of Paul Ridd, is fully and consistently implemented across the NHS.
- The Welsh Government must ensure there are enough learning disability nurses in Wales to provide support for people throughout their lifespan including: early years, child and adolescent services, adult services, older age and end of life care. This must include increasing pre- and post- registration learning disability nursing and post-registration nursing education.
- The Welsh Government must ensure every health board and trust in Wales has at least one learning disability consultant nurse. Health boards, higher education providers, social care and independent providers must also ensure they have a pathway for learning disability nurses to advance in their careers.
- NHS Wales and employers must facilitate time for nurses to study, Health Education and Improvement Wales must commission post-registration nursing education and universities must establish learning disability consultant nurse and advance practice nursing courses.
- The Welsh Government must ensure accurate information on out of area and out of country placements is collated and published. Independent and social care providers must invest in learning disability nursing to ensure care should be provided closer to home.







