RIGHT **CARE**

RIGHT **TIME**

RIGHT **PERSON**

RIGHT **PLACE**

Equity of **Access** and **Outcome**

The future role of RNLDs in supporting
people with learning disabilities to
achieve the best health possible

Contents

Acknowledgement

I would like to thank all those who have worked to produce this report to inform the strategic and future direction of Registered Nursing Learning Disabilities (RNLD) in Northern Ireland (NI). The publication of this report is both timely and appropriate as we face many challenges in meeting the health needs of our population. However, as nurses, we have the opportunity to make a real difference, in line with the ambition of *Health and Wellbeing 2026: Delivering Together* and the implementation of recommendations from other relevant reports, reviews and public inquiries.

It is vital that the RNLD workforce offers enough flexibility and innovation for future changes in service delivery models that meets public need. To support this, I firmly believe this report, which includes a proposed model for future RNLD services, will have a valuable impact in the further development of learning disability services here as nurses take on more complex and expert roles.

Moving forward, we need to work to improve access to services and support transformational change, whilst improving on recruitment and retention of registered nurses in learning disabilities.

I am confident that implementation of the future model and recommendations proposed within this report will help to achieve this for people with learning disabilities and their families.

Maria McIlgorm
Chief Nursing Officer
DoH

Foreword

As co-chairs of the RNLD Regional Strategic Workforce Development Group we are pleased to present *Equity of access and outcome: the future role of Registered Nursing Learning Disabilities (RNLDs) in supporting people with learning disabilities to achieve the best health possible.*

This paper outlines a future model to maximise the RNLD impact towards recognising the abilities and meeting the health and care needs of people with a learning disability across Northern Ireland (NI).

We celebrate the fact that people with learning disabilities are living longer. However, we also acknowledge that they often experience complex health and care needs, health inequalities and a shorter lifespan compared to the general population.

People with learning disabilities access care from a wide range of health and social care (HSC) services including general practice, community health and social care, secondary care and general hospital services. Nonetheless, many experience challenges accessing health and care services. Whilst RNLD's make up a small percentage of the overall nursing registrant workforce, when required, their skills and expertise can have a significant positive impact on the lives of people with learning disabilities, their families and carers. Therefore, ensuring a nursing workforce with the right skills, knowledge and behaviours who can provide the right care at the right time and in the right place for people with learning disabilities across the life course, is a priority for the Chief Nursing Officer (CNO).

Key to this will be ensuring that we have a RNLD workforce, working as part of the wider health and social care team, who can respond effectively to the needs of people with learning disabilities using a biopsychosocial approach.

The proposed model within this paper strives to strengthen the nursing contribution across all sectors within the interdisciplinary team and will ensure that, when required, RNLDs expertise will be available through specialist services within an equitable, timely, safe and effective manner. It recognises the RNLD contribution across the lifespan in: promoting wellness and prevention of ill health, self-management, anticipatory care through early intervention, responding to deterioration and acute needs, and providing monitoring and treatment of long-term conditions including palliative and end of life care. Furthermore, as part of the interprofessional team, using a biopsychosocial approach, RNLDs will support the biological, psychological, and social well-being of people with a learning disability from early years to the end of life.

This report should be considered in the context of other relevant reviews, inquiries and strategic work including:

- The Review of Learning Disabilities Nursing undertaken by the Department of Health (DoH 2022)
- Implementation of the Nursing and Midwifery Task Group (NMTG) Report and Recommendations (2020)
- Development of a new Adult Learning Disability Service Model and Framework for Children with disabilities which both form part of the Learning Disability Strategic Plan being led by the DoH
- Reform of Adult Social Care
- Implementation of the Mental Health Strategy (2021-2031)
- Development of Safe Staffing legislation

Moreover, we make a commitment to learning from the failings and progressing any pending recommendations from the Muckamore Abbey Hospital (MAH) Public Inquiry and related Belfast Health & Social Care Trust (BHSCT) and Police Service Northern Ireland (PSNI) investigation in the progression of the proposed model for RNLDs in the future.

We recognise the current expertise and good practice provided on a daily basis by RNLDs in NI, and we strongly advocate that this model is adopted to better serve people with learning disabilities and the RNLD workforce. Throughout the development of this report, we heard from a wide range of stakeholders and are grateful to everyone who helped to inform the future direction of the work of RNLDs in NI.

Linda Kelly
Chief Executive
NIPEC

Suzanne Pullins
Executive Director
**of Nursing**
Northern HSC Trust

Introduction

1

During 2020 and 2021, a review of Learning Disabilities nursing was undertaken by the Department of Health (DoH) on behalf of the then Chief Nursing Officer (CNO) for Northern Ireland (NI). This work included participants sharing their vision for the future role of the Registered Nurse Learning Disabilities (RNLDs) and identifying areas for improvement and reform within the profession.

As a follow up, in September 2022, the current CNO commissioned the Northern Ireland Practice and Education Council (NIPEC) to establish a Regional Strategic Workforce Development Group (hereafter referred to as the Development Group) to rapidly build on previous learning reports and consider a new model for RNLDs.

In line with evidence-based practice and population health data, a proposed future model for the RNLD workforce is presented within this report which aims to provide timely access to services, reduce variation and improve outcomes for people with a learning disability across the lifespan.

This model will promote the availability of a suitably skilled and resourced registrant learning disability workforce, primarily focused on supporting people to live in their community. Furthermore, the model will enable the workforce to be strategically planned across primary, community, secondary and hospital care, including specialist learning disability services. Recommendations to support implementation of the proposed model for RNLDs are also presented within this report.

Background

2
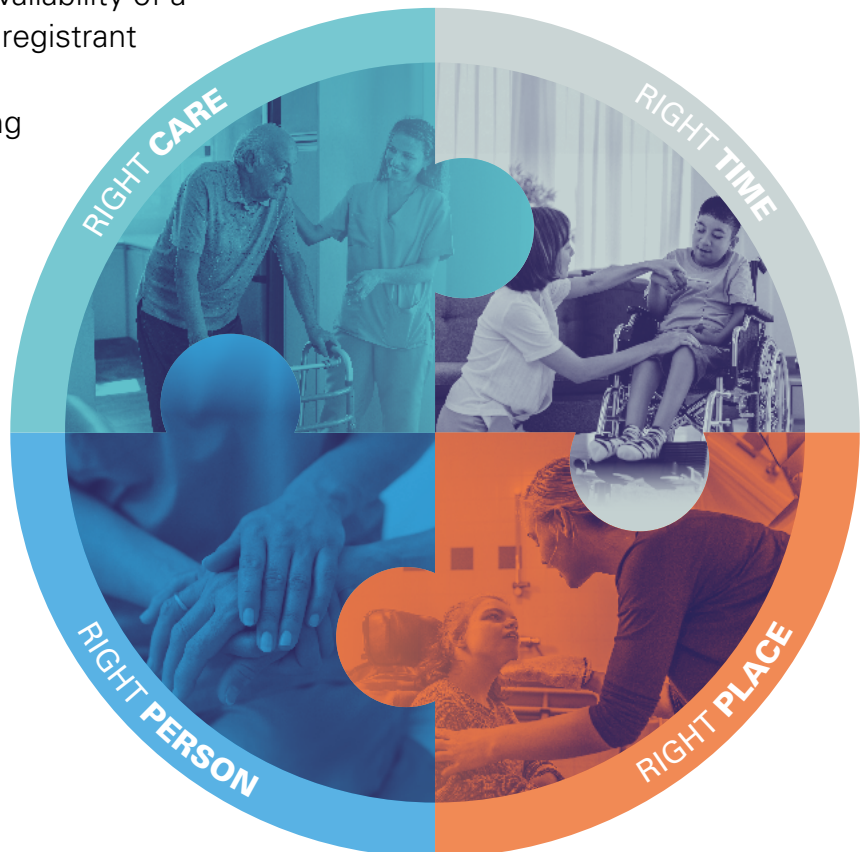
Within NI it is estimated that there over 40,000 people with a learning disability, which equates to 2% of the current population (Appendix 1).

At present, within NI health policy, the term 'learning disability' is defined as having the following three criteria:

- the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence);
- with a reduced ability to cope independently (impaired social functioning);
- which started before adulthood with a lasting effect on development.

Source: Equal Lives (DHSSPS; 2005, p18)

The National Institute for Health and Care Excellence (NICE) advises that a learning disability is defined by three core criteria [NICE, 2015]:

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

Note: the term 'intellectual disability' is becoming increasingly used internationally.

RNLDs at the point of registration are qualified to work with both adults and children with learning disabilities. They work collaboratively with colleagues to promote human rights and seek to promote and maintain the health and well-being with the overarching goal to empower individuals to achieve their full potential.

Additionally, RNLDs have expertise and skills that often are used to identify and support the population of people with developmental needs.

Over 99% of people with learning disabilities in NI live outside hospital settings with family members or in community-based facilities and make use of general healthcare services.

The current DoH policy relating to people with learning disabilities in NI is Equal Lives (DHSSPS, 2005). This requires health and social care to deliver services that first and foremostly recognise the citizenship of people with learning disabilities. Services provided by RNLDs should reflect the ambitions of Health and Wellbeing 2026 - Delivering Together (DoH, 2016), and the future learning disability strategic plan which is currently being developed by the DoH. This report proposes a future model for RNLDs and will inform the development of any interdisciplinary future service wide model.

2.1 Impact of Muckamore Abbey Hospital Public Inquiry

In proposing this model, the Development Group took cognisance of the on-going investigation relating to Muckamore Abbey Hospital including:

- A Review of Leadership and Governance at Muckamore Abbey Hospital' (MAH), in July 2020 which exposed gaps in the system of support for people with learning disabilities. A Review of Leadership & Governance at Muckamore Abbey Hospital (health-ni.gov.uk)
- Belfast Health and Social Care Trust and PSNI investigations into abuse at MAH
- The ongoing statutory Public Inquiry, into abuse of patients MAH to determine the range of circumstances that allowed the abuse to happen and ensure it does not happen again at any institution in NI. Terms of Reference (mahinquiry.org.uk)

Muckamore Abbey Hospital (MAH) was traditionally the largest specialist learning disability inpatient service in NI providing inpatient services for three of the Health and Social Care Trusts (HSCTs), and regional forensic and Psychiatric Intensive Care Unit inpatient services for NI. Over recent years the number of beds available for admissions have reduced and there is a programme of resettling for current patients into community living arrangements. In July 2023, the Department of Health has set June 2024 as the planned closure date for MAH into suitable accommodation in their local communities.

It is likely that there will be few RNLDs in NI that will not have some connection to the MAH through undertaking a placement in the hospital as part of their undergraduate training, working in the hospital at a point in their career, or knowing someone who works or has worked in the hospital. In March 2024, around 10% of RNLD's on the NMC register with an address in NI were involved in an aspect of the safeguarding process relating to the abuse within MAH. In this context the on-going investigation and associated learning will have a lasting impact on the public, the profession and role of RNLD's in NI in the future.

Purpose and Methodology

3

The work requested of NIPEC by CNO was taken forward through the development of a RNLD Strategic Workforce Development Group (Appendix 2: Terms of Reference). This work was informed by the Regional HSC Workforce Planning Framework Six Steps Methodology to Integrated Workforce Planning (DHSSPS, 2015). The work of the group was supported by a RNLD Expert Reference Group and a RNLD Communities of Practice (Appendix 3: for Terms for Reference for these two groups).

The Development Group aimed to propose a model for a RNLD skilled workforce to undertake and deliver therapeutic and clinical assessment and intervention across both inpatient and community services as part of the interdisciplinary team. In the development of the proposed new model, the Development Group have taken account of:

- ✔ Evidence based and best practice guidance

- ✔ Extensive feedback from staff, people with a learning disability and their families

- ✔ Learning from the review/inquiry into Muckamore Abbey Hospital and other events/incidents

- ✔ The current and projected population health profile of people with a learning disability

- ✔ Strengthening the Commitment: NI Action Plan (2014)

- ✔ The DoH strategic drivers, including the CNO Professional Vision for the Future (2023)

- ✔ Analysis of a scoping exercise undertaken by the Development Group which gathered a range of information regarding the current RNLD workforce in the HSC Trusts (Appendix 4)

- ✔ Data on the RNLD workforce provided by the DoH in 2023 during the writing of the report

- ✔ Analysis of a scoping exercise undertaken by the Development Group to gather information regarding the governance and accountability structures of RNLDs within HSC Trusts (Appendix 5)

- ✔ Models of best practice in United Kingdom (UK) and Republic of Ireland (ROI)

- ✔ Findings of major investigations across UK and ROI

The starting point should be that the healthcare needs of this population should be understood and met in general healthcare services including primary, community, secondary or hospital care.

RNLDs provide a core role within this approach, particularly where meeting health and care needs requires more specialist support in order to ensure equity of outcome.

Reflections and feedback from People with a Learning Disability, those close to them and Staff

The development of the model considered the learning from the comprehensive evidence gathered in the DoH Review of Learning Disabilities Nursing and the experience of people with a learning disability and those closest to them. In addition, staff were asked to reflect and feedback on their experience of the current model of RNLD service provision. Feedback and reflections are presented below.

People with a Learning Disability

- RNLD can really help me when I am sick
- Not everyone can access an RNLD
- Different services in different places

Those close to people with a learning disability

- Recognition of the role of the RNLD in ensuring continuity of care for the person with a learning disability and their families. Need for more equitable services – both in hospital and community
- Recognition of the role of the RNLD in making reasonable adjustments when healthcare is needed
- Recognition of the advocate role provided by RNLDs especially when there is no family available

RNLDs

- The role of the RNLD is not always valued
- Other professions are unsure of the role of the RNLD
- Lack of career pathway and career opportunities
- Professional accountability arrangements are not always clear
- Lack of senior positions filled by RNLDs

Interdisciplinary team members

- The role of the RNLD is not clearly defined
- Unclear regional strategic direction for this field of practice
- Governance processes and structures could be strengthened

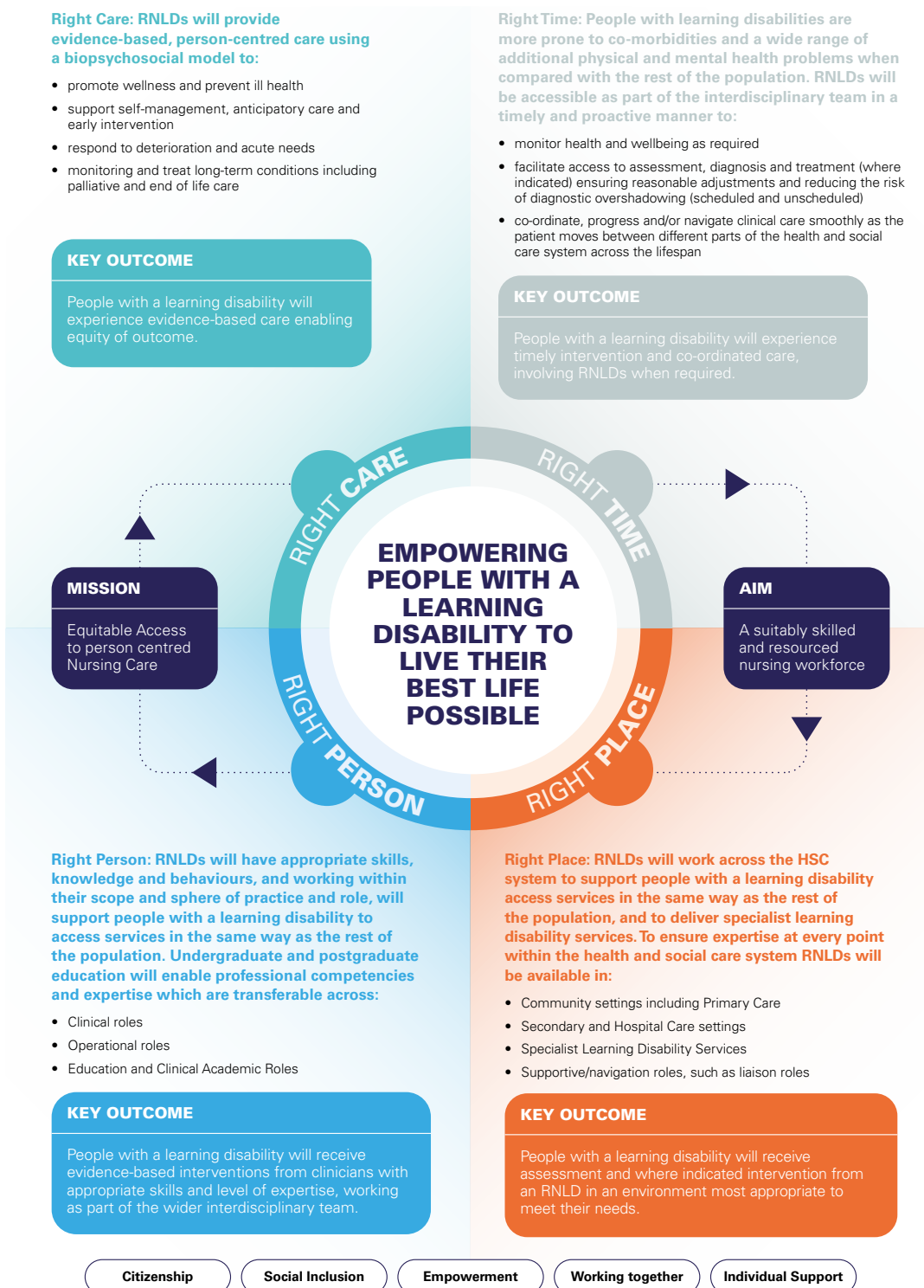Reflections and feedback highlighted the significant variation in service provision, with contributors giving very poignant examples from their lived experience. This information has shaped and informed the design of the proposed new model (Figure 1) for the RNLD workforce and the subsequent recommendations to ensure establishment of a sustainable model.

Full details of the RNLD Model are available in Section 12 & 13.

RNLD Model: The Right Care, at the Right Time, in the Right Place by the Right Person

5

Figure 1

Right Care: RNLDs will provide evidence-based, person-centred care using a biopsychosocial model to:

- promote wellness and prevent ill health
- support self-management, anticipatory care and early intervention
- respond to deterioration and acute needs
- monitoring and treat long-term conditions including palliative and end of life care

KEY OUTCOME

People with a learning disability will experience evidence-based care enabling equity of outcome.

Right Time: People with learning disabilities are more prone to co-morbidities and a wide range of additional physical and mental health problems when compared with the rest of the population. RNLDs will be accessible as part of the interdisciplinary team in a timely and proactive manner to:

- monitor health and wellbeing as required
- facilitate access to assessment, diagnosis and treatment (where indicated) ensuring reasonable adjustments and reducing the risk of diagnostic overshadowing (scheduled and unscheduled)
- co-ordinate, progress and/or navigate clinical care smoothly as the patient moves between different parts of the health and social care system across the lifespan

KEY OUTCOME

People with a learning disability will experience timely intervention and co-ordinated care, involving RNLDs when required.

RIGHT **CARE** RIGHT **TIME**

EMPOWERING PEOPLE WITH A LEARNING DISABILITY TO LIVE THEIR BEST LIFE POSSIBLE

MISSION
Equitable Access to person centred Nursing Care

AIM
A suitably skilled and resourced nursing workforce

RIGHT **PERSON** RIGHT **PLACE**

Right Person: RNLDs will have appropriate skills, knowledge and behaviours, and working within their scope and sphere of practice and role, will support people with a learning disability to access services in the same way as the rest of the population. Undergraduate and postgraduate education will enable professional competencies and expertise which are transferable across:

- Clinical roles
- Operational roles
- Education and Clinical Academic Roles

KEY OUTCOME

People with a learning disability will receive evidence-based interventions from clinicians with appropriate skills and level of expertise, working as part of the wider interdisciplinary team.

Right Place: RNLDs will work across the HSC system to support people with a learning disability access services in the same way as the rest of the population, and to deliver specialist learning disability services. To ensure expertise at every point within the health and social care system RNLDs will be available in:

- Community settings including Primary Care
- Secondary and Hospital Care settings
- Specialist Learning Disability Services
- Supportive/navigation roles, such as liaison roles

KEY OUTCOME

People with a learning disability will receive assessment and where indicated intervention from an RNLD in an environment most appropriate to meet their needs.

Citizenship   Social Inclusion   Empowerment   Working together   Individual Support

The recommendations aim to align to the CNO vision for the future of the professions in NI and establish a sustainable RNLD workforce model to meet the current and the future needs of the learning disability population of NI.

In May 2023, the Chief Nursing Officer for NI launched the Vision for the professions of Nursing and Midwifery. This included strengthening the focus on four strategic areas of work:

- Workforce/Workforce Planning
- Education and Training
- Quality Assurance framework
- Career pathways

A summary of the key areas of focus outlined in the recommendations are presented in Figure 2 below. ***Full details are available in Section 18***.

Figure 2: Recommendations

✅ **Workforce/workload Planning**
Support on-going evidence-based workforce planning that ensures the availability of a suitably skilled and resourced registrant workforce.

✅ **Quality Assurance Framework**
Establish structures and processes that provide robust governance, professional leadership, accountability and quality assurance for RNLD services and demonstrate impact on outcomes for people who have a learning disability.

✅ **Education and Training**
Ensure RNLDs have appropriate access to post graduate education to support the delivery of safe and effective person-centred care, and professional development throughout their career.

✅ **Career Pathways**
Ensure career pathways enable RNLDs to develop the necessary knowledge, skills, confidence and leadership required to enable people with a learning disability to have equity of access and outcomes from RNLDs working in primary, community, secondary and hospital care settings.

# Population health needs of people with a learning disability in NI

6

It is recognised that the term 'learning disability' can be difficult to define and the language used over the years has evolved and can be different at a regional, national, and international level.

The life expectancy of people with learning disabilities has increased considerably over the past 40 years. More people with learning disabilities are living into older age and many children with complex physical healthcare needs and a learning disability are living into adulthood. This increased life expectancy has been influenced by a number of developments in healthcare including, technology use outside of hospital settings and potentially, though not yet evaluated, developments aimed at improving access to healthcare services for people with learning disabilities including the introduction of the Direct Enhanced Service and Health Facilitators in 2011 (PCC, 2019), the Learning Disability Service Framework (DH 2015), HSC Hospital Passport (PHA 2017), and Guidelines of caring for people with learning disabilities in general hospitals (RQIA, 2018).

There are several sources of data relating to population prevalence of people with a learning disability in NI, however none are considered definitive. A rapid review of the literature was undertaken, and a position paper developed on *Population Prevalence - Learning Disability* (Appendix 1) providing a high level estimate to support the development of the proposed RNLD model.

The minimum, or lower end population prevalence estimate was approximately 40,500 persons, or 2% of the total population in NI in 2023. The estimated prevalence of learning disability population by HSC Trust, based on the 2023 GP list size, and assuming that 2% of the population have a learning disability, was calculated as illustrated in Figure 3.

Figure 3: Estimated prevalence of learning disability population by HSC Trust, based on the 2023 GP list size, and assuming that 2% of the population have a learning disability
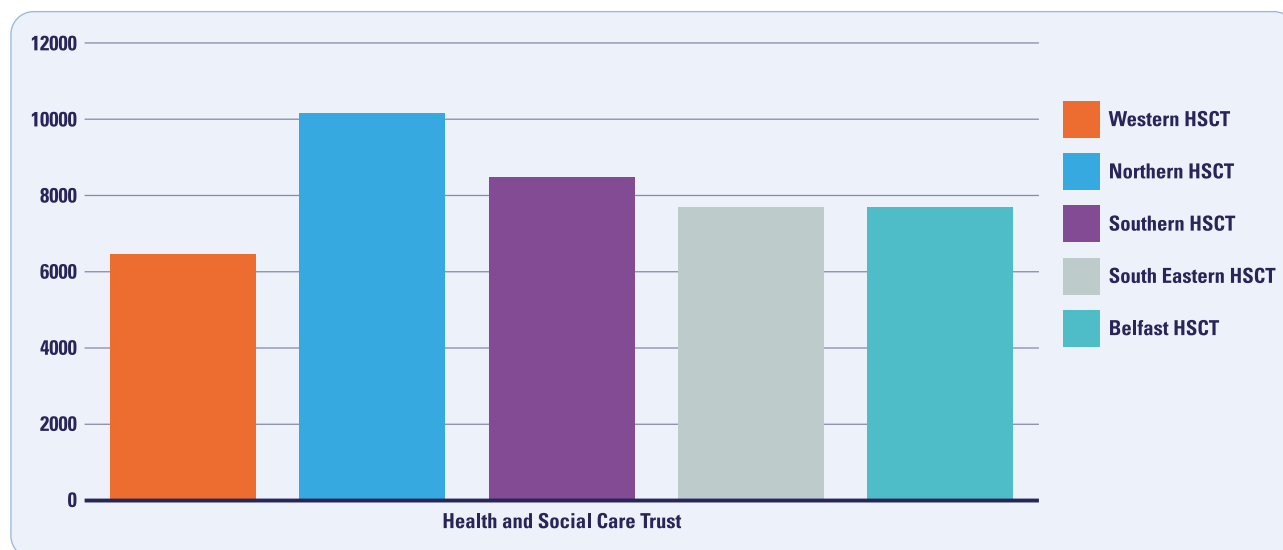
Source: *Population Prevalence NI-Learning Disability Position Paper Appendix 1*

6.1 Patterns of mortality and morbidity among people with learning disabilities

There was no Northern Ireland specific population level health information relating to the physical or mental health of people with learning disabilities available to inform this work. This is in stark contrast to population health needs information collated in other UK countries and within the ROI.

In the absence of NI specific data, population information relating to the health needs of people with a learning disability from elsewhere in the UK and ROI was reviewed to inform this work. This included:

- the LeDeR (Learning from lives and deaths) project in England, (LeDeR 2020)
- the IDS TILDA project in the Republic of Health (IDS TILDA 2023)
- Health needs assessment of people with learning disabilities by NHS Scotland (Truesdale and Brown, 2017).

There is a consensus across a range of recent research reports that the health of people with learning disabilities differ in important ways from that of the wider general population and that this needs specific attention.

People with learning disabilities have been found to have a consistently more complex physical health needs and a higher rate of comorbidities. The most recently reported list of long-term conditions include, mobility impairment, incontinence, respiratory disorders, skin conditions, sensory impairment, mental health needs, constipation, epilepsy, falls and gastric reflux.

In addition, any of the physical conditions common in older people, occurred earlier and more frequently in people with learning disabilities.

Figure 4: Age-standardised avoidable, treatable and preventable mortality rates (per 100,000), people with learning disabilities 2018, 2019 and 2020 (excluding deaths from COVID-19), and the general population in 2019
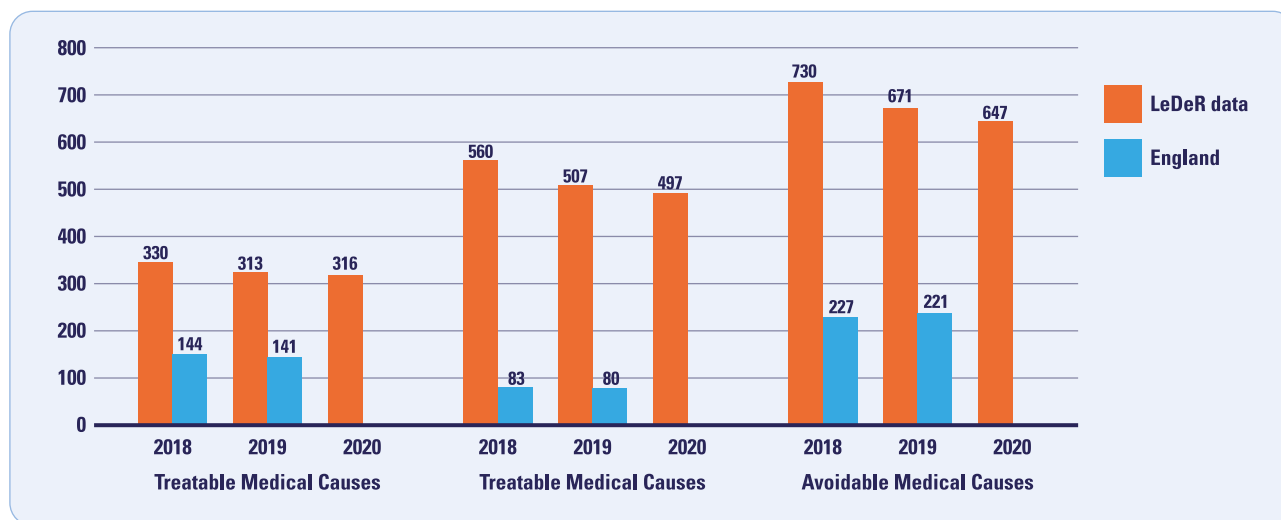
The findings of the LeDeR Annual Report state that, despite improvements on previous years, in 2022/23 42% of all the reported deaths of people with a learning disability were avoidable, that is they were caused by conditions that can be mainly avoided through effective prevention or treatment (Figure 4).

A review of the records by Kinnear et al (2018) of 1023 people with learning disabilities in Scotland reported that 98.7% had multimorbidity as outlined in Figure 5.

**Figure 5: Prevalence of physical health conditions**
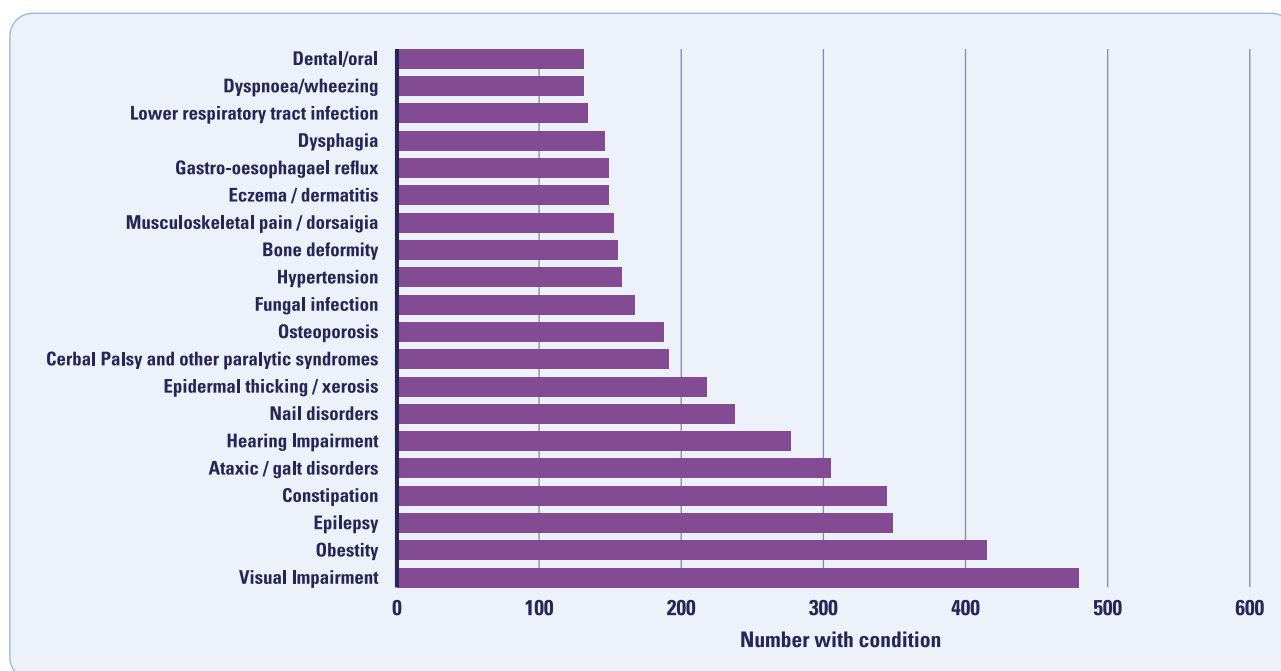
(Kinnear, D. et al, 2018)

The overall life expectancy of people with learning disabilities has increased in the past few decades although is still lower than the wider UK population. The LeDeR (2019) project in England found that people with respiratory disease rather than cardiovascular disease was the most common cause of death among people with learning disabilities. Following analysis of the records of 7154 people with learning disabilities who have died between January 2016 and December 2019, it reported that:

- For death notified in 2019, the median age of death of males was 61 and for females it was 59. This was 22 years younger for males and 27 years younger for females compared the wider UK population.
- 85% of people in the general population died aged 65 and over, this figure was 37% for people with learning disabilities.
- People with learning disabilities died from an avoidable medical cause of death twice as frequently as people in the general population (44% of deaths of people with learning disabilities; 22% of deaths in the general population).
- People with learning disabilities died 4.25 times more from treatable medical causes than other members of the population (34% compared to 8%) as presented at Figure 6.

Figure 6: Percentage of avoidable death of people with a Learning Disability
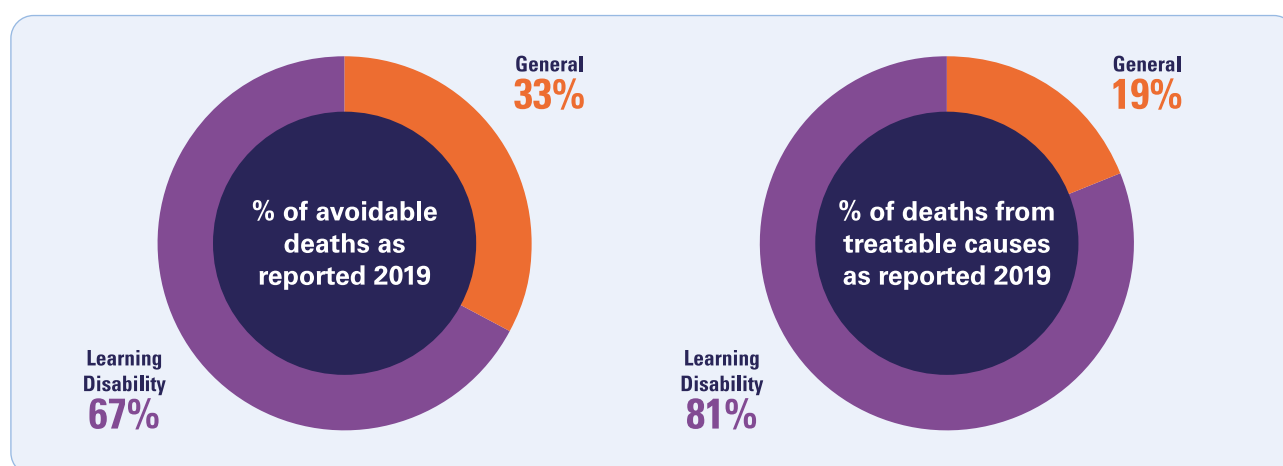
(LeDeR 2019)

- The COVID-19 pandemic highlighted 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, with far greater mortality rates in younger adults, compared to the general population (LeDeR, 2021).

6.2 Mental Health and Neurodevelopmental Disorders

The incidence of poor mental health was reported in 52% of people with learning disabilities surveyed in the IDS TILDA study in 2017. The rates of people with dementia and depression is higher among people with learning disabilities compared to the general population. Commonly reported mental health issues include: anxiety disorders, depression, psychosis, affective disorders, obsessive-compulsive disorder, schizophrenia and dementia. Research suggests that up to 50% of people with autistic spectrum disorder also have a co-occuring learning disability. In addition people with a learning disability are more likely to have Attention Deficit Hyperactivity Disorder (ADHD) with a longer life course. Many of these conditions could be identified earlier and in some cases prevented or more effectively managed, or their impact limited with timely, outcome focused and effective interventions by RNLDs and the wider interdiscplinary team.

6.3 Use of general hospitals by people with learning disabilities

An analysis of 16,998 admission records of people with learning disabilities to general hospitals in the Republic of Ireland between 2016 – 2020 reported that people with learning disabilities proportionally made more use of general hospitals than other members of the general public. The top reasons for contact with general hospitals related to:

- Respiratory
- Gastrointestinal (including teeth)
- Neurological
- Ear, nose and throat (ENT)
- Cardiac conditions.

(DOODY et al 2021)

Similar comprehensive data is not available in NI. Information on the healthcare needs of people with a learning disability, accessing hospital care is not routinely collected in all hospitals in NI.

6.4 Summary of Key Learning: Population health needs of people with a learning disability in NI

✔ There is an absence of robust population level data about the health needs of people with learning disabilities in NI and their interactions with a range of health and social care services

✔ Learning disability population prevalence is estimated to be 2% of the total population in NI in 2023

✔ The life expectancy of a person with a learning disability has increased which is to be celebrated

✔ The number of people with learning disabilities making use of general healthcare is expected to increase

Morbidity

✔ People with learning disabilities have been found to have a consistently more complex physical and mental health needs and a higher rate of comorbidities

✔ There is a significantly higher rate of mental health issues experienced by people with a learning disability compared to the rest of the population

Mortality

✔ People with learning disabilities die younger and have a higher rate of avoidable deaths than other members of the general population

RNLD Workforce Availability in NI

7

Between April 2022 and March 2023, the total number of nurses with the Nursing and Midwifery Council (NMC) with a registered address in NI was 21,348, of these 838 were RNLDs Figure 7 (NMC 2023). It should be noted that registered nurses can hold more than one qualification.

**Figure 7: Total RNLD Nurses in NI – in Year Comparison (NMC 2023)**
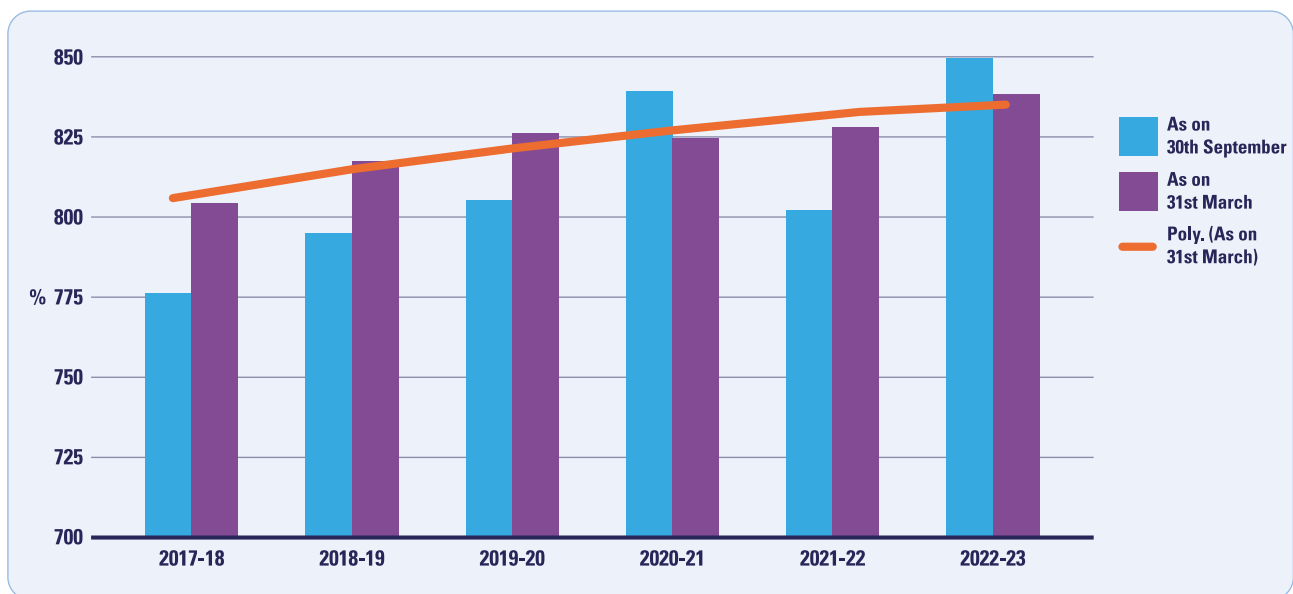
It is important to note that although there is a modest and steady increase in the number of RNLDs entering the NMC register over the past 5 years, newly qualified RNLDs don't always opt to work in Learning Disabilities Services.

The employment destination of nurses post registration is currently not tracked in NI; therefore, it is difficult to rigorously assess where RNLDs take up post outside HSC Trusts. However, Queens University Belfast (QUB) carried out a survey of three cohorts of students who completed a pre-registration learning disabilities programme (n=105 graduates) during the period 2017 – 2019. The information indicates that RNLDs are taking up posts outside of traditional HSC Trust Learning Disabilities Services as outlined in Figure 8.

Figure 8: Newly qualified RNLDs employment destination

Of those 105 graduates, 77% (n=81) completed an employment destination survey.
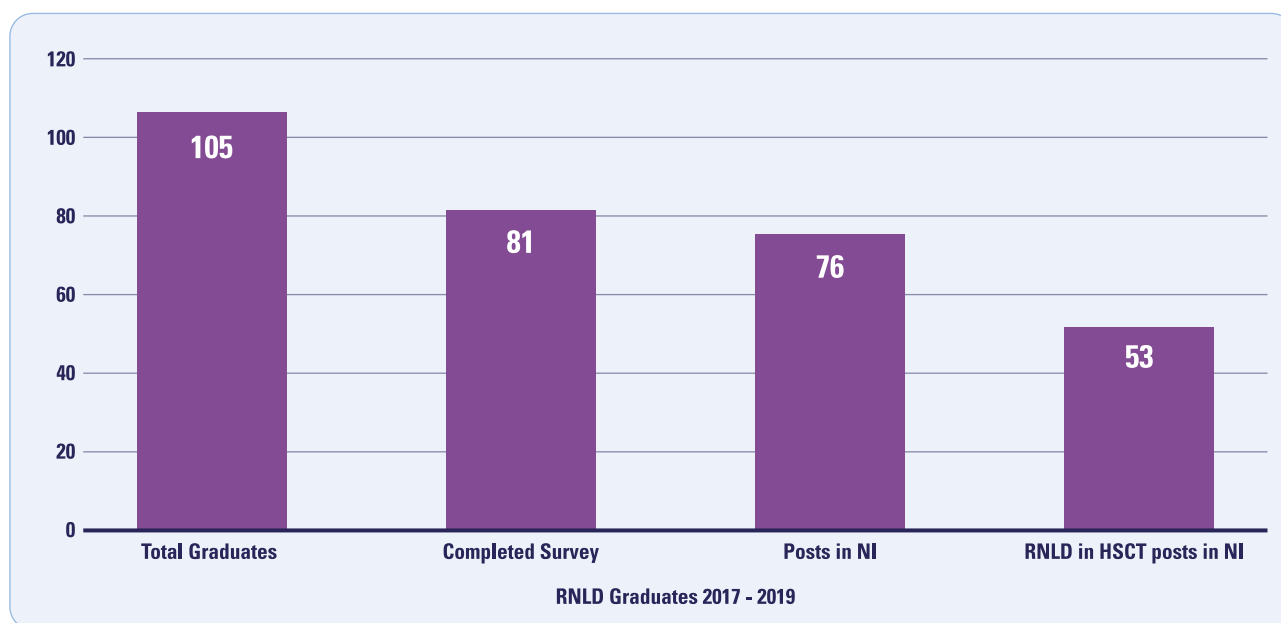

(Marsh et al 2023)

In the survey 3 newly qualified RNLDs (3.7%) reported taking up posts outside NI and 17 (21%) reported taking up posts outside Learning Disabilities services. It is not clear from available data where the remainder of the newly qualified RNLDs were employed.

7.1 HSCT Scoping Survey Analysis

Analysis of a scoping survey undertaken by the Development Group across the 5 HSC Trusts in NI found that 40.5%, (344 headcount) RNLDs with addresses in NI worked in HSC Trust Learning Disability services (Information provided by HSC Trusts) as presented at Figure 9. Information on where the remaining 59.5% (505 headcount) RNLDs were working was not available.

Figure 9: RNLDs on NMC register with addresses in NI (2023)
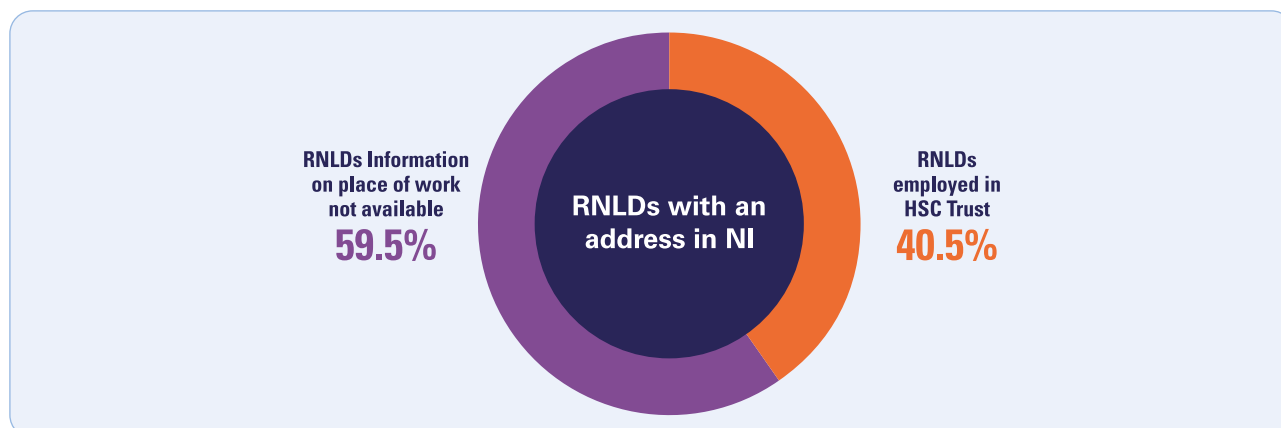
Data submitted by the DoH presented at Figure 10 evidences the overall downward trajectory of RNLDs employed in the HSC Trusts since 2015-2023 by headcount and WTE.

Figure 10: Staff numbers employed in HSC Trusts by Head count and WTE (DoH 2023)
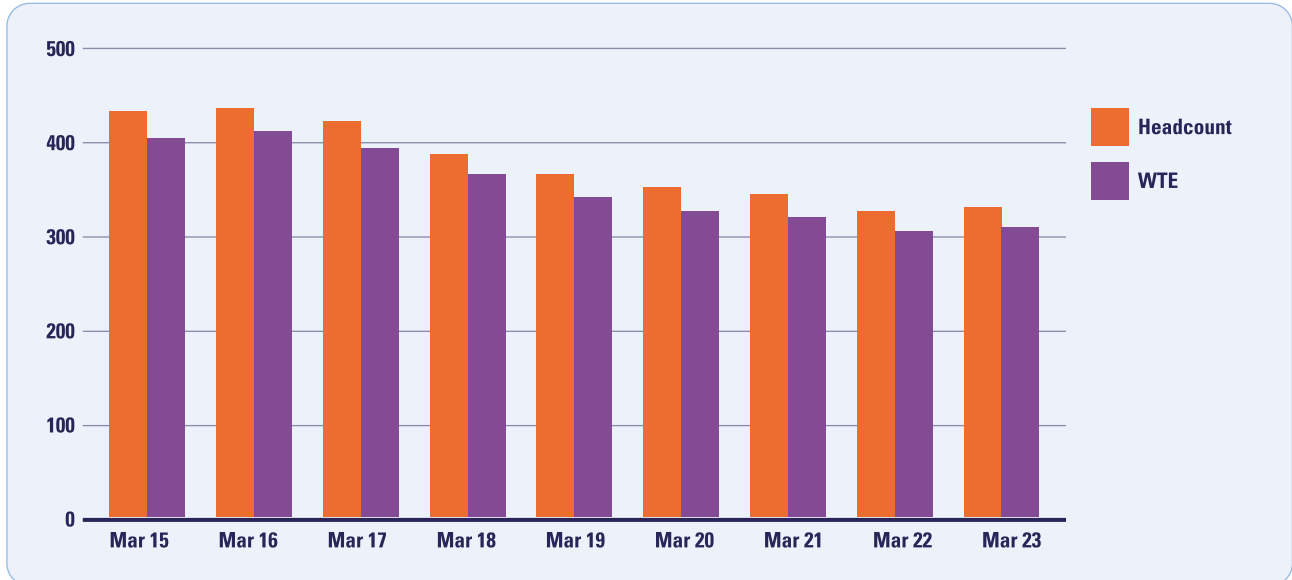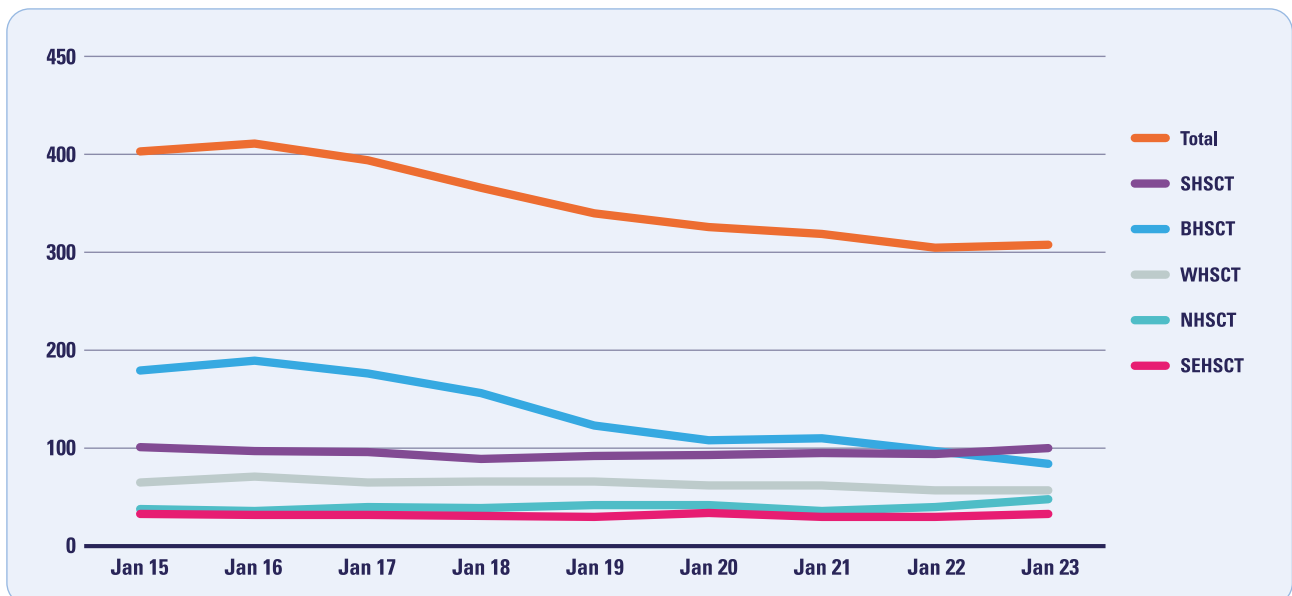

Figure 11 highlights the number of RNLDs employed in each of the HSC Trusts in NI since 2015. Part of this downward trajectory may be attributable to RNLD vacancies between March 2020 and March 2023 which averaged at 56 WTE per year.

Figure 11: RNLD Employment by HSC Trusts in NI (DoH 2023)

7.2 Nursing Support Staff

The aforementioned downward trajectory of RNLD's working in HSC Trust Learning Disability Services would appear to be mirrored in learning disability nursing support staff as presented Figure 12. (information based on data provided from the DoH). Availability of adequate numbers of nursing support staff are integral to the nursing team, providing a skill mix to support the delivery of person-centred nursing care. Any decrease in the nursing team is likely to impact on care delivery.

Figure 12: Nursing Support Staff working in HSC Trust Learning Disabilities Services (DoH 2023)
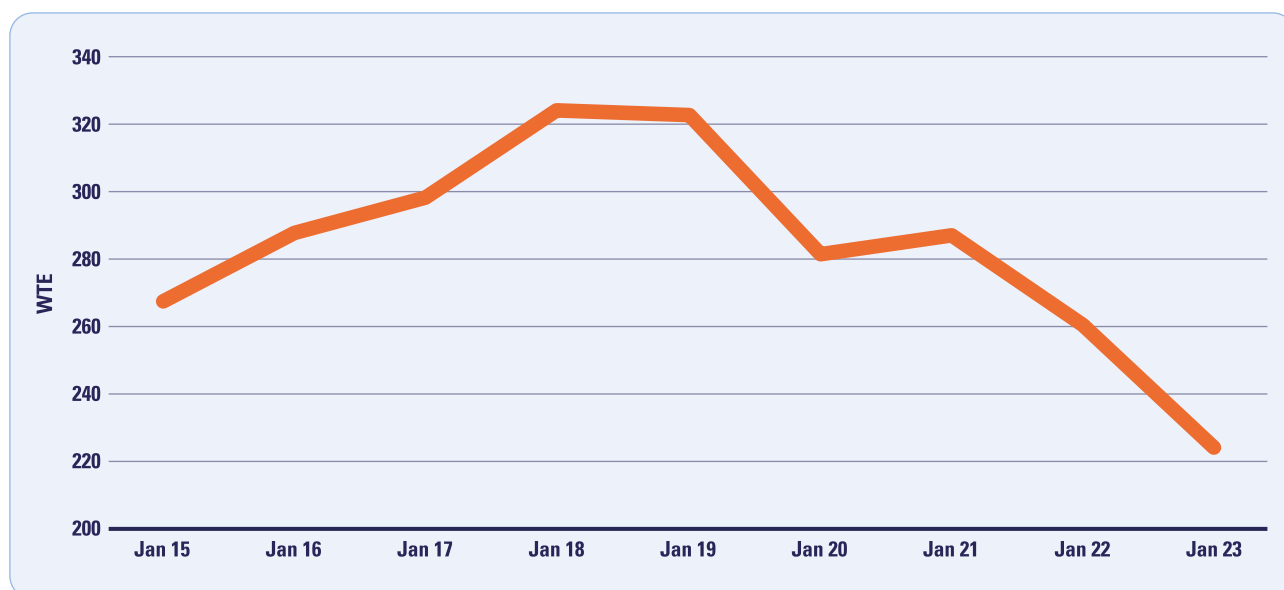
7.3 Banding

The majority of staff employed in Learning Disabilities services are working at Band 5 and Band 6, with a small number working in senior posts at Band 7 and above, the most significant decrease is in the number of Band 5 posts across the HSC Trusts Figure 13.

Figure 13: WTE by AfC Band – percentage by Agenda for Change (AfC) Banding in HSC Trusts in NI (DoH 2023)
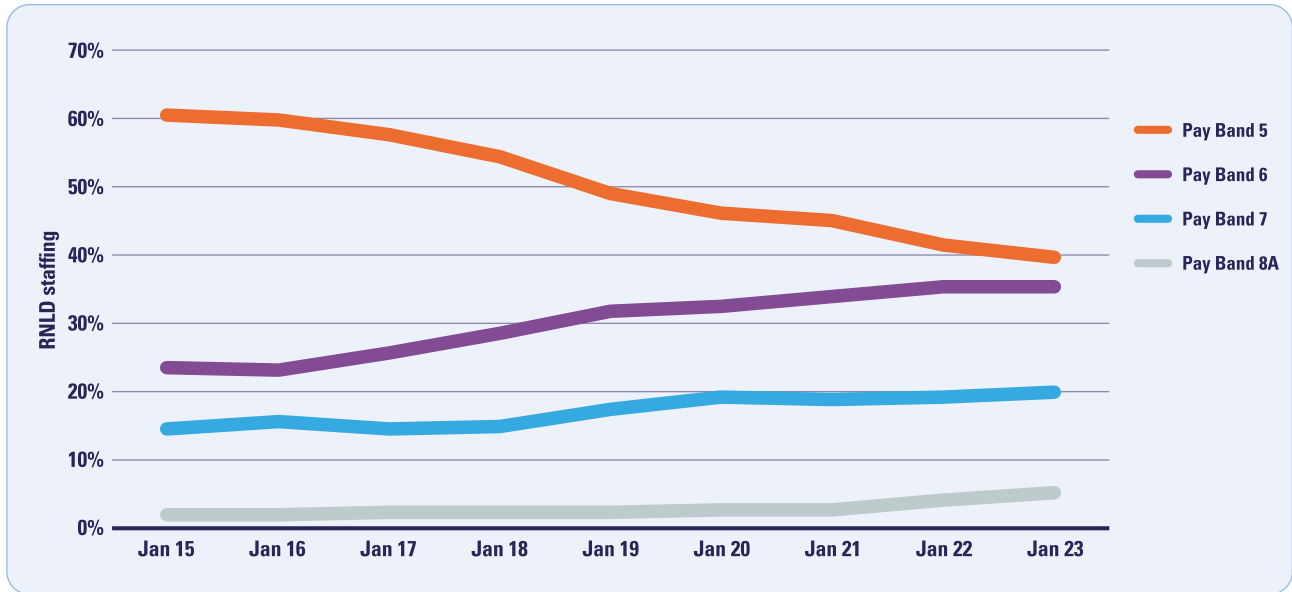
However, the trend would indicate that there has been some investment to increase the number of senior RNLD nursing roles. While this goes in some way to meet the Nursing and Midwifery Task Group Report and Recommendations (NMTG 2020) further investment is likely to be required in senior nurse roles and especially around promoting specialist and advanced clinical roles. Delivering Care the Policy Framework for Nursing and Midwifery Workforce Planning in NI (Delivering Care | HSC Public Health Agency (hscni.net)) has made some investment to grow the RNLD workforce as detailed in Section 10.

7.4 Age Profile

In March 2023, 77 (23%) of RNLDs working in the HSC Trusts were aged 50 years and above as presented in Figure 14. Whilst this is significant, it remains lower than the overall NMC reported age profile statistics for registered nursing workforce with addresses in NI which reflects 45.6% of the registered workforce are over the age of 50yrs (NMC 2023).

Figure 14: RNLD headcount by age band employed in HSC Trusts (DoH 2023)
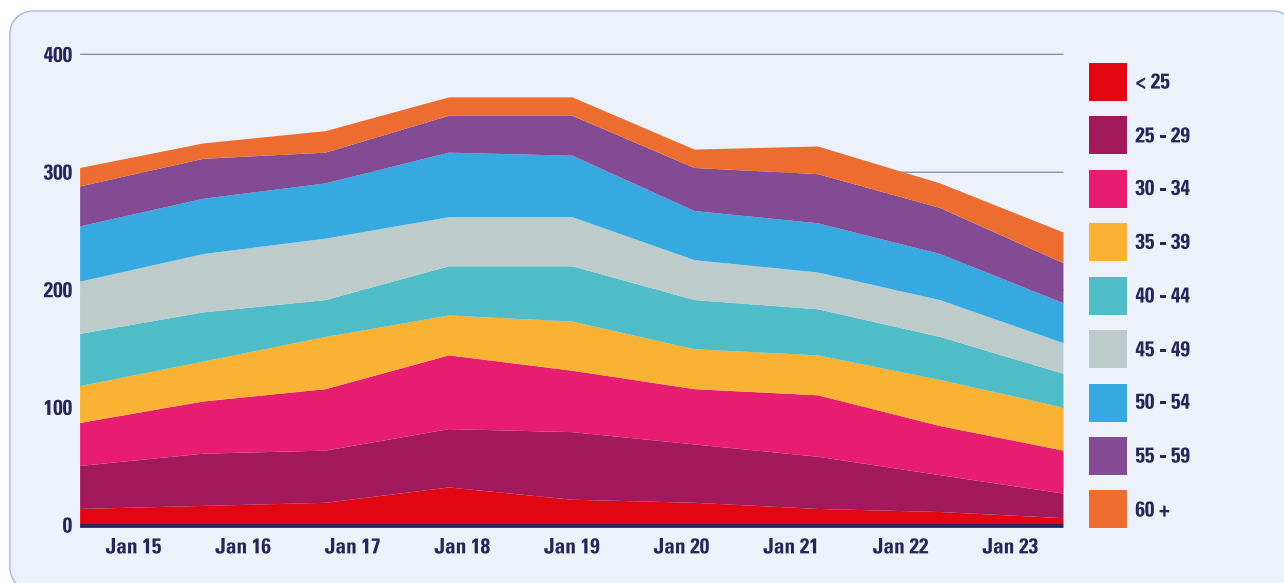
7.5 Absence

There have been ongoing challenges within the RNLD workforce with significant levels of sickness absence as demonstrated in Figure 15. This field of nursing sickness rate is slightly above the overall nursing sickness absence rate in 2022/23 for all HSC registered nursing recorded at 8.5%.

Figure 15: HSC Trusts RNLD Nurse sickness absence – percentage of scheduled hours lost (DoH 2023)
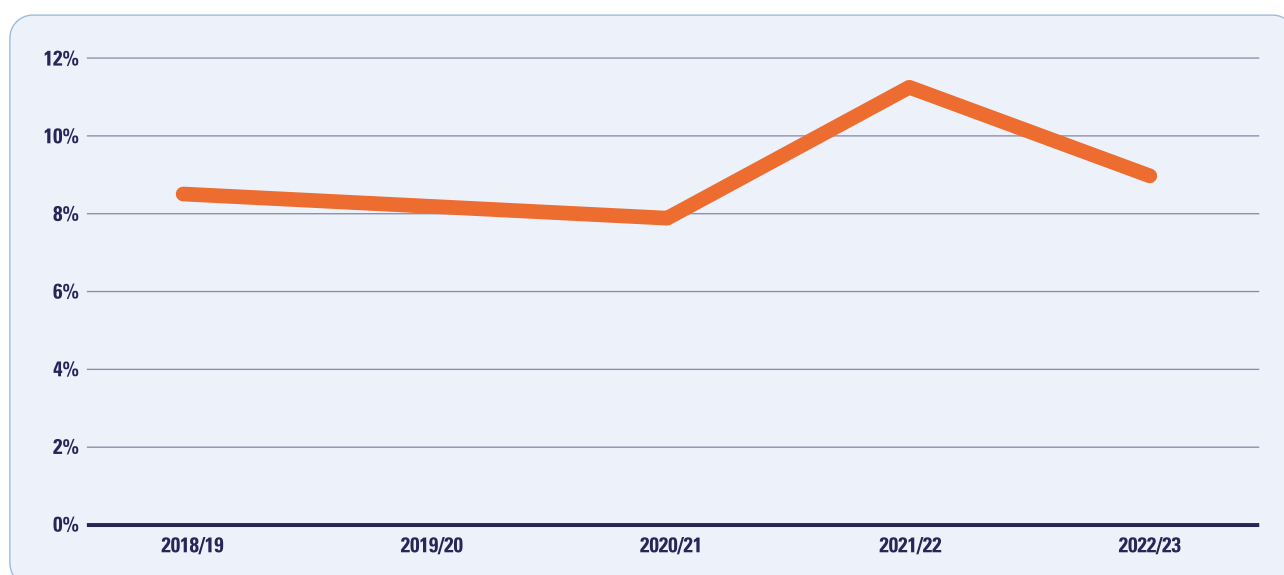
In summary, the seeming reduction of available RNLD staff, both registered and non-registered, coupled with an aging workforce and levels of sickness are likely to place strain on current learning disabilities nursing services. In addition, low levels of senior specialist and advanced clinical posts are likely to impact delivering the ambition for transformation of services outlined in Delivering Together (2016).

7.6 Agency Usage

The use of agency staff to address deficits in RNLD workforce availability varied considerably across HSC Trusts and was captured in an audit over a 3-month period from August – October 2023 by the Development Group. The findings would indicate that the use of agency nursing staff are rarely used outside hospital services.

- Two HSC Trusts with no inpatient services reported they did not use agency staff for RNLD posts over the 3-month period.
- Three HSC Trusts reported they had used agency staff to address the deficit RNLD posts, with 87% of these hours used to cover band 5 RNLD posts in-patient settings.
- In services where agency staff were used to address the deficit in RNLD availability, in most cases the agency registrant did not have a RNLD qualification. This has potential implications in the delivery of safe and effective care.

7.7 Summary of Key Learning: RNLD Workforce availability

✓ In 2023 838 RNLDs with an address in NI were registered with the NMC

✓ 40.5% RNLDS work in HSC Trusts, no information was available on where the other 59.5% work

✓ There is no robust regional process for tracking where RNLDs take up post on registration and continue to practice outside HSC Trusts

✓ Limited data indicates as few as 66% of newly qualified RNLDs may take up posts in specialist Learning Disability services

✓ Between March 2015 – March 2023 there has been a 23.83% decrease in (WTE) RNLDs employed in HSC Trusts with a 49.94% decrease in Band 5 RNLD posts

✓ Vacancy rates for RNLDs employed in HSC Trusts averages at 56 WTE representing an 18% vacancy rate

✓ Agency staff are utilised primarily in inpatient settings and in most cases these agency registrants do not have a RNLD qualification. This has potential implications in the delivery of safe and effective care.

Current Model for Registered Nursing Learning Disabilities

8
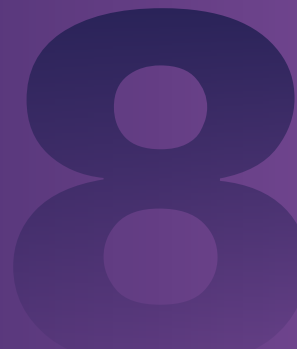
8.1 RNLD Staff Employment Areas

Reduction in long stay inpatient population means that more individuals who traditionally had their nursing care delivered in hospital settings are now living in the community. Figure 16 presents were RNLDs, by whole time equivalent (WTE) are employed in HSC Trusts across service areas including adult and children in-patient and community settings and designated roles across adult and children services.

Figure 16: Regional HST Trust service area employment of RNLDs. (DoH 2023)
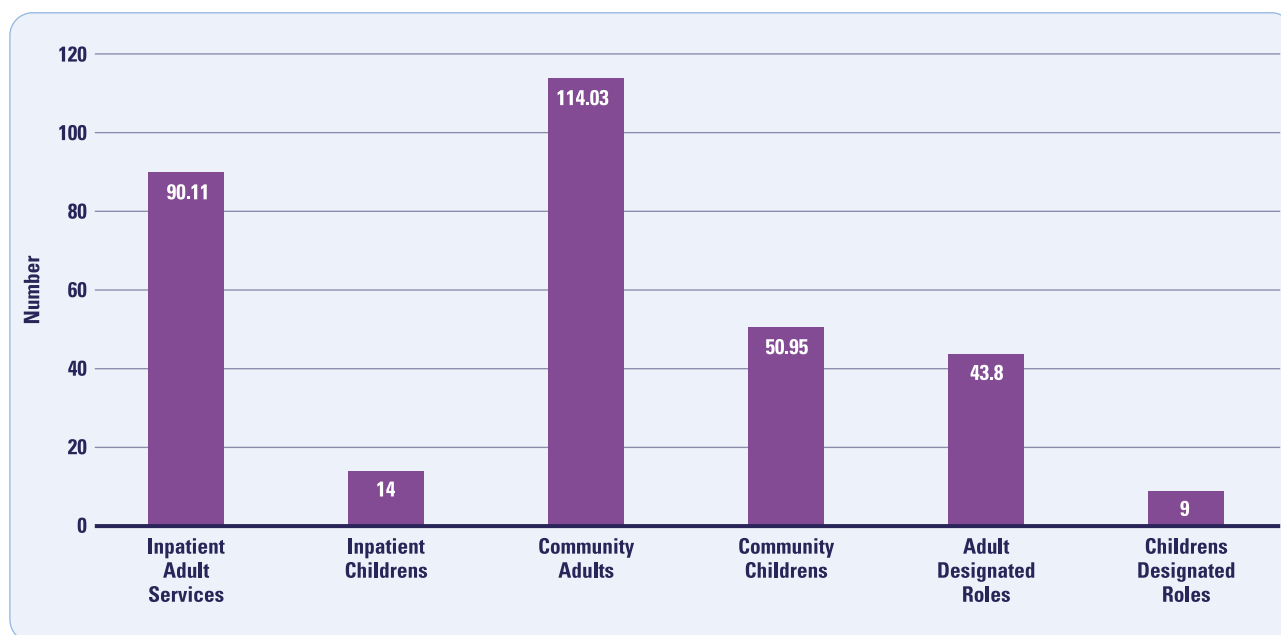
In the current configuration of Learning Disability services across HSC Trusts, how and where RNLDs are employed varies and is presented at Figure 17. Given this information it is reasonable to conclude that service delivery and access to services for people with a learning disability varies across organisations. Additionally, the scoping exercise undertaken as part of this project would suggest that separate and parallel services to general services have been established to meet the needs of people with a learning disability, e.g epilepsy services. There is a recognition this risks sub-optimal services for people with a learning disability, which may exacerbate or contribute further to health inequalities in this group.

Figure 17: RNLD Service area employment by HSC Trust NI
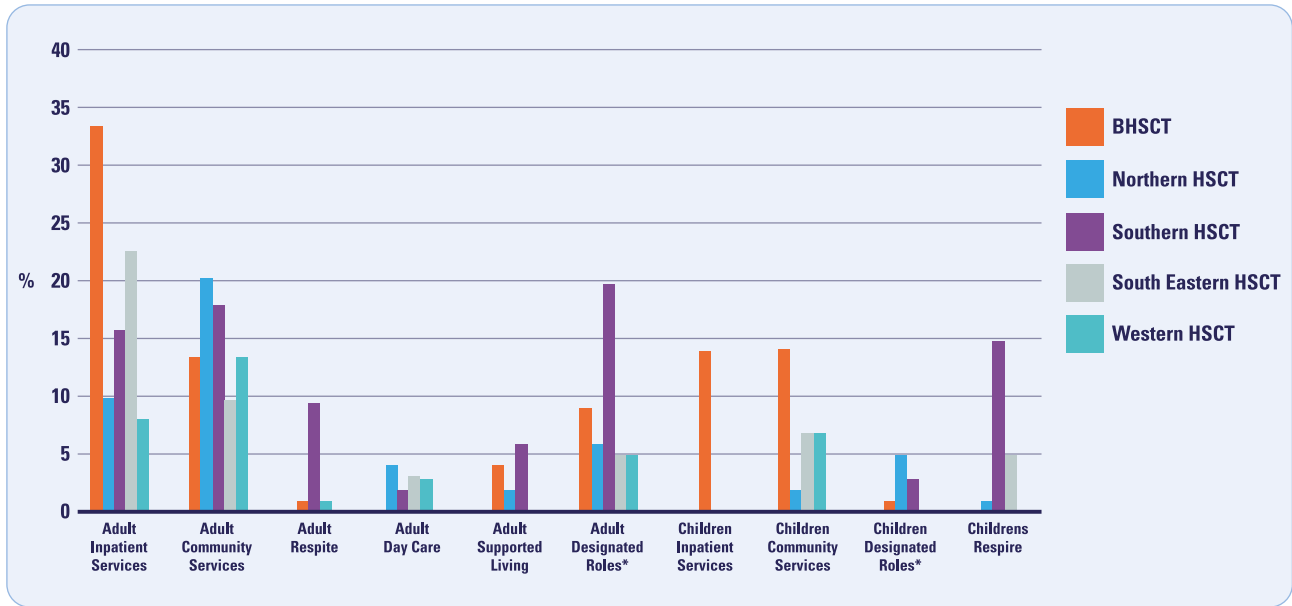
*see designated roles section 8.7.1

Figure 18 suggest that a higher number of RNLDs work in community services. RNLDs continue to provide an invaluable service to meet the needs of people with a LD when hospital care is required.

However in order to better meet the health and care needs of people with a learning disability, in the proposed workforce model there is a renewed focus on the roles of RNLDs to:

• promote wellness and prevent ill health,
• support self-management, anticipatory care and early intervention,
• respond to deterioration and acute needs,
• monitoring and treat long-term conditions including palliative and end of life care.

It is anticipated this will be best facilitated by having RNLD expertise at every point across the system to support people with a learning disability.

Figure 18: RNLD Employment area in HSC Trusts (DoH 2023)
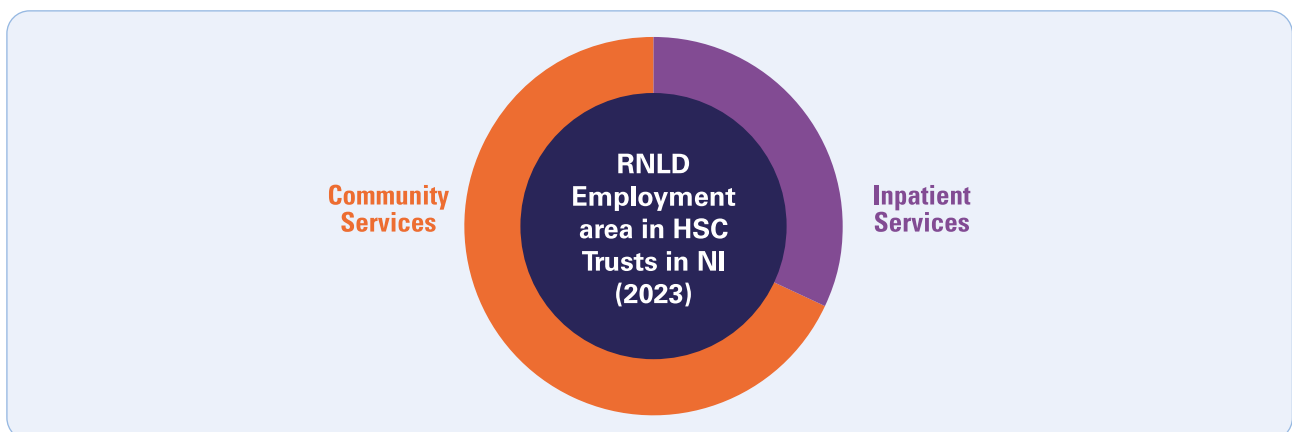
8.2 Inpatient Services

There are 4 HSCTs in NI providing inpatient services for people with learning disabilities. Muckamore Abbey Hospital serves 3 HSC Trusts; the BHSCT, NHSCT and SEHSCT represented in Figure 19.

Figure 19: Inpatient Service provision (PHA and SPPG 2023)

Trust	Commissioned Beds	Number of beds	Comments
BHSCT	MAH	87 beds (19 low secure beds. (note recent years have noted a reduction in beds available for admission of patients. There is currently a resettlement programme in place.	To note: at the time of reporting 24 of the 87 beds were occupied – the outcome of a consultation on the future of MAH has confirmed a date for closure of June 2024.
BHSCT	Iveagh Children and Young People's Centre	6 beds	
NHSCT	Holywell	3 beds	
SHSCT	Dorsy	10 beds	
WHSCT	Lakeview	10 beds	

The policy direction since 2005 has been that no-one should live in a specialist learning disability hospital and that hospital inpatient care should focus on assessment and treatment only for those people for whom this cannot be made available within a community setting. Whilst resettlement of long stay patients living in hospital settings NI has been slower than anticipated and not fully achieved, over recent years there has been a renewed focus and effort to ensure this policy intention is achieved, with a steady decline in the number of people with a learning disability being cared for in inpatient units.

8.3 Community Services

Arrangements for the delivery of Adult and Children's Community based Learning Disability Services vary significantly across the five HSC Trusts, and in some cases vary within Trusts. RNLD's work in a range of community and secondary care services. In some HSCT's, RNLD's are employed in specific Community Nursing Learning Disability roles, working across a wide range of settings.

8.4 Children's Services

RNLDs have a significant role as part of the interdisciplinary team in ensure timely approaches to identifying, assessing and monitoring the needs of children with a learning disability and young people with complex needs. The employment of RNLDs in adult services compared to children services is demonstrated at Figure 18.

Increasingly, RNLDs are working across the full range of children and young people's services, including childrens nursing in hospital, child and adolescent mental health nursing and community children's nursing. Roles also include health visiting and school nursing, where it has been shown that early year's support can lead to people with a learning disability having healthier and more fulfilling lives, not just during childhood and adolescence but also throughout their adult years.

These roles enable children and young people with a learning disability to access and use health and social care services, respecting them and family involvement as partners in their own care.

The new model recognises learning disabilities nursing roles critical function in children's services, including supporting the period of transition from children to adult services; ensuring co-ordinated timely and effective access to specialist assessment, support and intervention and facilitating ongoing support.

8.5 Custodial system and Prison Healthcare Settings

There is increasing recognition of the significant role that RNLDs can have in forensic services through working with people in contact with, or at risk of contact with the criminal justice system. Moreover, there is a growing expectation that prison services employ RNLDs, either based within primary or secondary prison healthcare services. There are currently 3 WTE RNLDs employed within the NI prison healthcare services. Whilst these posts are not specifically funded for RNLD staff, there is a recognition of the wealth of skills and expertise provided and the value this role brings to the expanding integrated healthcare team. Currently healthcare within the NI Prison service is exploring providing a learning disability pathway for those living in prison.

Future RNLD models of care and workforce planning within NI must consider how to best meet the health and social care needs of this population, especially in relation to anticipatory care and helping to provide support to prevent offending/re-offending and supporting discharge and integration back into the community.

8.6 Social Care Settings

Exploration of place of employment has revealed that RNLD's continue to take up posts in HSC Trust Adult Community based social care services in the following settings:
• Residential Setting (including short breaks)
• Supported Living
• Day Care

Many of the RNLD's working in these posts are working in roles that do not require an RNLD registration or in some cases a professional qualification. Analysis of the data submitted as part of this project would suggest that 42 staff (12%) of 345 (headcount) of the HSC Trust's RNLD workforce are working in social care settings. The number of RNLDs working in social care settings outside the HSC Trusts is currently not known.

Future models must enable RNLDs to maximise their impact in these settings. The future direction of nursing, as outlined in the Nursing and Midwifery report and recommendations (2020) includes maximising the contribution of nursing to population health outcomes, making every contact count (MECC) and improving public health. This can be achieved through transformation of RNLD roles across social care settings through co-production, biopsychosocial interventions and inter-agency facilitation of evidence-based practice. For example, RNLD's will be cognisant of emerging evidence such as the high incidence and prevalence of falls in community-dwelling older adults with a learning disability, aged 35 years and older (Hoe et al 2019). With their knowledge and skills RNLDs will be aware that this can be reduced with screening and management of falls risk, thereby maintaining mobility and enhancing a high quality of life.

8.7 Variation of RNLD Service Planning

As part of this work a scoping exercise was undertaken by the Development Group. This identified a range of proposed service developments across HSC Trusts which included future RNLD roles. Of concern, there was significant variance in proposed service developments and they did not appear to be consistent with regional strategic direction.

8.7.1 Variation of RNLD Roles

There are very significant variances across HSC Trusts in relation to where RNLD's are employed, their Agenda for Change (AfC) Banding and their roles. Appendix 6 shows the wide range of designated job titles/roles and banding for posts that RNLDs are employed in across the HSC Trusts. These roles are presented at Figure 20.

Figure 20: Designated roles for RNLDs across HSC Community and Inpatient Settings

Designated RNLD roles/settings	
• Behaviour Nurse	• Acute Liaison
• Forensic Nurse	• Mental Health Liaison
• Health Facilitator	• Transition Nurse
• Epilepsy Nurse	• Complex Health Needs
• Dementia Nurse	• Trainee/RNLD Consultant Nurse
• Practice Educator Facilitator	• Monitoring Officer
• Nurse Development Lead	• Day-care Nurses

In NI two HSC Trusts have appointed a total of three RNLD Acute Liaison Nurses in general hospitals. This is a relatively new development in NI. By contrast, RNLD Acute Liaison Nurse roles are widely available and have been established in Scotland, England and Wales for the last 20 years.

There have been recommendations to appoint RNLDs in acute liaison roles for a number of years in NI (GAIN, 2010, RQIA, 2014) however, to date progress in this area has been limited.

Some services for people with a learning disability have developed in a way that is not consistent with the aim of inclusive healthcare and in some cases limits access to services. This is particularly evident where Trusts that have set up separate but parallel services for people with learning disabilities, for example, epilepsy services for people with a learning disability, continence for people with a learning disability.

The model proposes regionally consistent services for all, with integrated RNLD roles to support equity of access and outcome, and access to specialist learning disability services where needed.

8.8 Summary of Key Learning: Current RNLD Service Model

- Variation exists in interdisciplinary service models across the HSC Trusts

- RNLD job descriptions, AfC banding and roles vary in apparently similar posts across HSC Trusts

- There are 116 (including 6 children) commissioned in-patient beds across 4 HSC Trusts however the majority of these beds are not available at present and have not been for the past 2 years due to workforce challenges

- The 5 HSC Trusts in NI provide Specialist Learning Community services which employ RNLDs

- A number of RNLDs work in social care settings that do not require a RNLD qualification

- Policy direction indicates that no-one should live in a specialist learning disability hospital. Specialist assessment and treatment should be available in the community with admission to in-patient care only when necessary and for the shortest possible period. However, services and workforce to fully support this shift have yet to be fully developed

- In HSC Trusts the slight majority of RNLDs are employed within community settings, with approximately one third employed in Children's services

- The contribution of RNLD has been increasingly recognised over recent years within prison health care, children's and neurodevelopmental services.

RNLD Learning and Development

9

9.1 Pre-Registration Commissioned Places

Population health data for people with LD is essential to inform effective workforce planning including workforce projections to meet the current and future health needs of people with a learning disability in NI. As part of effective regional workforce planning, there is a need for appropriate numbers of places on pre-registration learning disabilities nursing programmes to meet current and future population health needs.

Evidence to support the rationale for the number of commissioned places by the DoH on pre-registration programmes or alignment with the trajectory in workforce planning needs and population health needs is not fully available for NI. The DoH commissions pre-registration Learning Disability nursing places from Queens University Belfast (QUB), and Open University (OU) since 2019 (Figure 21). The OU four-year programme is available to health and social care support workers employed across a range of settings within HSC Trusts, who have a permanent contract and who work 26 hours or more in their substantive post.

The period between 2020/21 resulted in the highest number of commissioned places N =52 over the past 10 years. In 2023/2024, commissioned places returned to the original commissioned numbers of 38 due to funding pressures within the DoH (Figure 21).

Figure 21: Total DoH Pre-registration Commissioned Places for Learning Disabilities Nursing 2013-2023
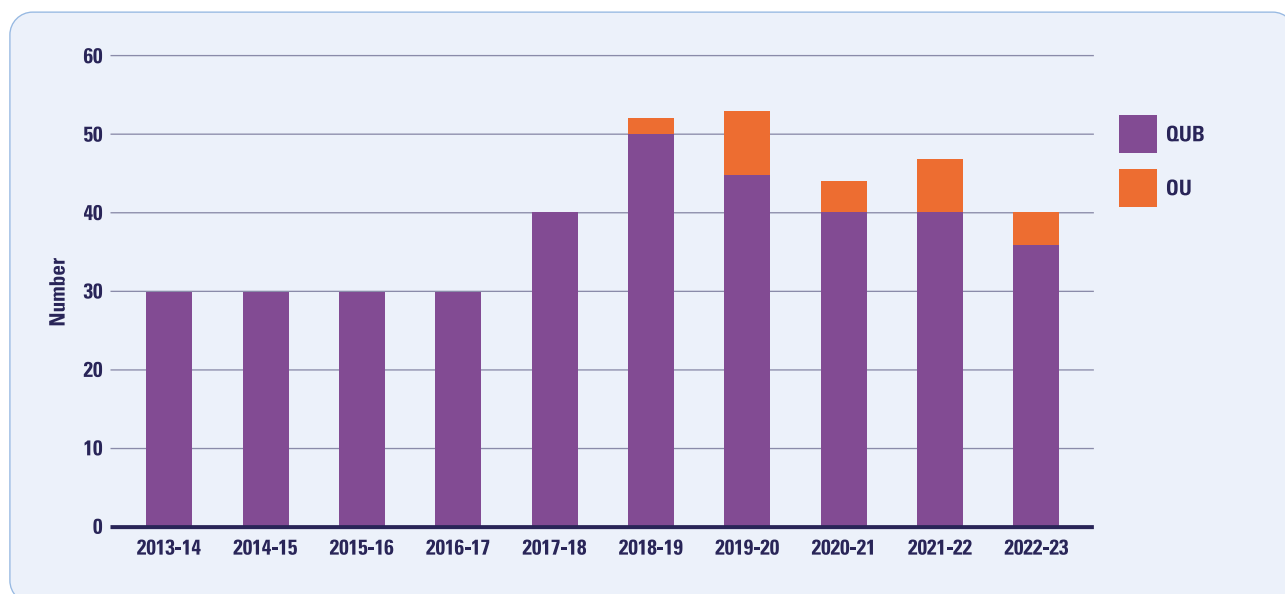
Northern Ireland, like other UK countries, has experienced a decline in the number of applications for learning disabilities pre-registration programmes. Information submitted from QUB and OU indicates that neither university has recruited their full cohorts of students on the pre-registration learning disabilities programme since 2020-2021. It is important to be mindful that this pattern is also evident across other pre-registration nursing programmes and not confined to learning disabilities nursing.

Whilst the learning disability pre-registration programme at QUB has achieved a student satisfaction rating of between 93-97% in successive National Student Surveys since 2020, a small number of students have been permanently withdrawn following progress committee decisions or due to personal reasons (see Figure 22).

Figure 22: QUB recruitment and attrition rate per class cohort

Cohort	Commissioned	Started	Permanent withdrawal
Sept 18	40	40	3
Sept 19	50	50	4
Sept 20	45	45	6
Sept 21	40	40	2
Sept 22	50*	35	2
Sept 23	36	32	1

*10 places commissioned for (Graduate Entry Masters) GEMs Programme which did not progress due to low number of applications

As presented in Figure 23 of the small number N=12 students who commenced the OU programme in 2020, 3 students withdrew and of the 2021 intake N=7, 3 students withdrew. Eight students commenced the 2022 intake and of these, one student switched from the learning disabilities programme to the mental health programme, the remaining students are still on course to complete as are the 3 students who commenced in 2023.

Figure 23: OU Pre-registration recruitment and attrition
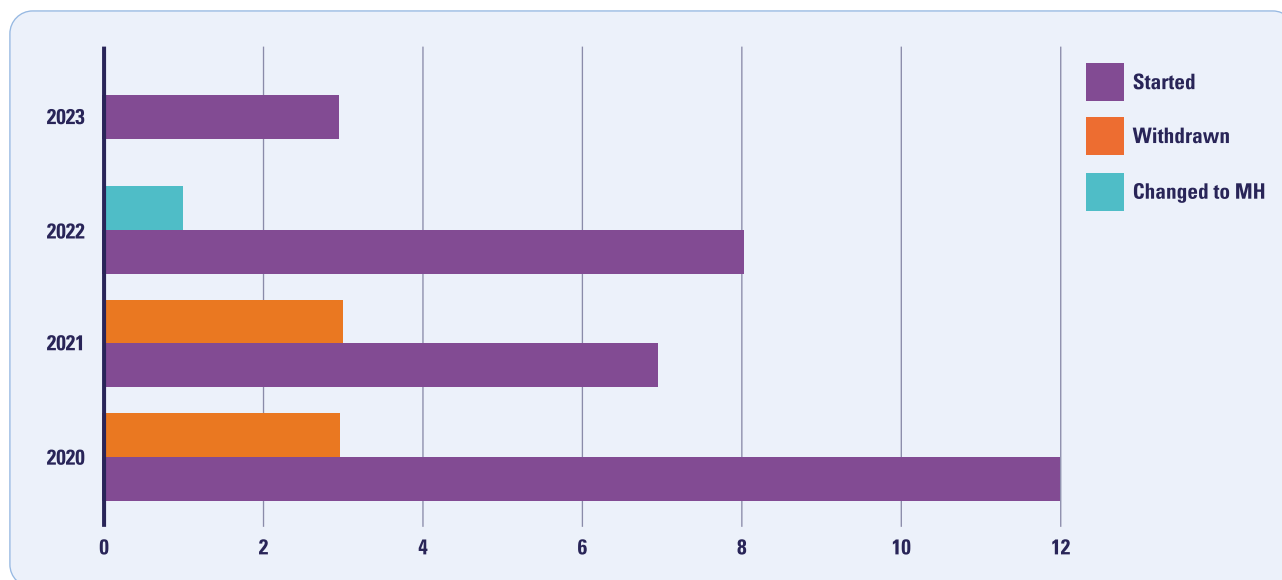
9.2 Post Registration Education Commissioning

The DoH supports regional commissioning of post registration education programmes across a number of education providers for the registrant workforce in NI. Significant investment (circa £11,000,000 planned in 2023) is annually committed to NMC approved programmes as well as other training and education aimed at developing a competent workforce to meet the needs of the population and support staff development.

Smaller fields of practice such as learning disability nursing often struggle to secure commissioned programmes as numbers of places requested from HSC Trusts fail to meet the cohort size. This is reported to be due to the reduced demand, smaller numbers within the overall workforce and the resulting challenges of releasing staff from their clinical roles.

In 2022 the then CNO commissioned a review of post registration education commissioning. The subsequent report made recommendations aimed at enhancing the commissioning and delivery of post-registration education for nurses, midwives, and allied health professionals in NI.

The review recommended that post registration education commissioning should consider switching from measuring cost (per place on programme) to impact on population health as value and outcome. It also recommended that strategic regional plans for post registration education, learning and development for the nursing workforce should focus on.

- maintaining safe and effective health care delivery
- transforming and developing new services
- meeting professional development needs to support and retain staff

The review also suggests that co-designed modules/programmes are essential in meeting the needs of the workforce.

37

9.3 Nursing and Midwifery Council approved and recorded qualifications

9.3.1 Specialist Practice Qualification

Specialist Practice Qualifications (SPQ) available in NI includes SPQ Community Nurse Learning Disabilities and Specialist Practitioner – Learning Disabilities. These programmes are important in the development of the RNLD workforce for the future enabling the provision of specialist support for people with a learning disability across adult and community settings Over the last 10 years, a total of 43 places on the SPQ programmes have been commissioned over four intakes (2013, 2016, 2021, 2022). The SPQ Learning Disabilities programme was last commissioned in 2021 in response to HCS Trusts identification of need that year. Since 2023 this programme is no longer available due to changes in the NMC standards for SPQ. However, SPQ Community Nurse Learning Disabilities continues to be NMC approved and is available in NI and has been commissioned as a two-year part time programme in the past six years. This was previously commissioned as a full-time programme.

9.3.2 Nursing Prescribing Qualifications

Over the past 10 years, there has been an increase in the uptake of nurse prescribing programmes across all fields of nursing practice as part of advancing nursing roles. This programme accounts for a significant portion of the post registration nursing commissioning budget annually. In the scoping survey undertaken as part of this project a small number of RNLDs were identified as holding NMC prescribing qualifications within learning disability nursing services across the HSC Trusts. Although there has been a reported increase in the uptake of these programmes by RNLDs the number of RNLDs with a prescribing qualification in HSC Trusts remains modest as presented at Figure 24 with a number having completed the programme but who are not on a Trust prescribing register.

Figure 24: RNLD Prescribing qualification by Trust (Adult and Children services)

9.3.3 Non NMC Approved Post Registration Education

A further scoping was carried out within Trusts to ascertain the range of education non NMC Approved programmes commissioned for RNLDs via the DoH education commissioning process from 2019–2022 in response to HSC requests. This exercise excluded education programmes delivered by the Clinical Education Centre (CEC). There is limited evidence that RNLD post-registration education commissioning, which is informed by HSC Trusts training needs analysis, is linked to professional strategic direction, or that learning and development is linked to population health needs. This scoping included short courses and standalone modules accessed across the three universities and the Royal College of Nursing (RCN). The results were concerning regarding educational development for this field of nursing, including the demand, uptake and completion of commissioned programmes by RNLDs:

- Of the 58 places commissioned for RNLDs, nine (n=9) RNLDs either withdrew or did not complete the education programme they had embarked on. 6 of the RNLDs who withdrew were all from the same HSC Trust.
- One HSC Trust stated that during the academic year 2020 to 2021 no RNLDs attended any commissioned programmes - COVID-19 pressures were cited as a significant factor.

The most commonly accessed Non NMC approved education programmes undertaken by RNLDs were:

- health assessment
- principles of assessing people with learning disabilities
- working with people with dementia
- the senior nurses tool kit (RCN programme)

Respondents highlighted that the programmes RNLDs have undertaken does not reflect the initial requests made, as programmes requested were frequently not viable due to the small number of applicants and funding availability.

It is suggested in a future learning and development model for RNLDs, a cost benefit analysis for post registration education in NI, which monitors value beyond unit cost/programme, would better demonstrate the benefits for the registrant workforce and impact on population health.

9.4 Summary of Key Learning: RNLD Learning and Development

Pre-registration

✔ In 2023 the number of commissioned part time pre-registration nursing places for RNLD nursing is at its lowest number in the past 3 years and at its lowest number for full time places in 6 years

✔ There is a decline in the number of applications for learning disability pre-registration programmes as a first choice

✔ A number of students do not complete their pre-registration learning disabilities nursing programmes

Post Registration

✔ There is limited evidence that RNLD post-registration education commissioning, which is informed by HSC Trusts training needs analysis, is linked to professional strategic direction, or that learning and development is linked to population health needs

✔ The programmes commissioned may not reflect the demand as decisions to commission can be based on meeting cohort size as a current measurement of value

✔ The number of RNLDs who have completed prescribing programmes remains low and a number who have are not on the Trust prescribing registers suggesting they are not utilising this qualification

✔ Specialist Nursing Qualification in Community Nursing Learning Disabilities has been commissioned as a two-year part time programme in the past six years, this was previously commissioned as a full-time programme

Career Pathway for RNLDs

10

Career planning and development is a very important part of continuous professional development (CPD) to guide nurses towards achieving their maximum potential. In NI career pathways map out the core roles for nursing and support staff, identifying the relevant knowledge, skills and experience required for the care setting with accompanying job descriptions. Career pathways, provide clarity of roles competencies and support in determining professional skill mix requirements at a clinical practice and senior leadership level.

The particular knowledge, skills and experiences of the RNLD are transferable across pillars of career development: clinical, operational/management, education and research posts. Currently, in NI, RNLDs are not well represented across any of these pillars, with challenges in succession planning, retention of current staff and the recruitment of RNLDs across the system.

Small isolated steps have been taken to address this in recent years, with funding of 20 posts in 2021/2022 across the 5 HSC Trusts to strengthen leadership and clinical roles through the Delivering Care Policy Framework (DoH 2019) including funding to support the appointment of:

- 5 Band 8b Consultant Nurse posts
- 5 Band 8a Advanced Nurse Practitioner posts
- 10 Band 7 posts Team Leader posts

There is an overall Career Framework guidance in NI available at https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-gidance-framework-nm-career-pathway09-12-21.pdf. Application of the framework through a RNLD Nursing Career pathway will facilitate the new RNLD model to improve:

- recruiting students to RNLD field of practice
- recruiting newly qualified RNLDs to take up nursing posts in services for people with learning disabilities
- ensuring we have the right workforce with the right skills knowledge and behaviours to meet the current and future needs of people with Learning Disabilities
- securing senior leadership and management nursing posts for RNLDs in Learning Disability Services

10.1 Advancing Practice

In NI new approaches have been recommended to ensure provision of Specialist and Advanced Nursing Programmes which incorporate the prescribing programmes to support career pathways for registrants. Advanced Nursing Practice Framework | Department of Health (health-ni.gov.uk) Adopting this approach will support the development of RNLDs career pathway through investment for advancing roles through effective workforce planning.

An RNLD career pathway focusing on the following areas: clinical, operational, education and clinical academic, would align this field of practice to the CNO strategic Vision for Nursing and Midwifery 2023-2028. In addition to supporting nurses to pursue the range of career progression options, the pathway provides clarity of the impact RNLDs make as part of interdisciplinary working and helps raise the profile of the profession.

Leadership capability and capacity will be integrated throughout each pathway. Where new RNLD roles are being introduced it should be supported with clear processes overseen by the HSCT Executive Directors of Nursing. Transformation of roles for RNLDs should be based on regional strategic direction and sustainable workforce planning, including the development of advancing professional roles for nursing. Advanced Nursing Practice Framework | Department of Health (health-ni.gov.uk)

Building leadership capability and capacity is required within the new model to ensure that the model is sustainable and care is configured to meet the learning disability population nursing needs. Where new RNLD roles are being introduced, the impact for the person with learning disabilities, their families and the interdisciplinary team needs to be clear.

10.2 Summary of Key Learning: Career Pathway for RNLDs

✔ A specific RNLD Nursing Career pathway does not currently exist for NI

✔ Currently, RNLDs are not well represented in professional nursing leadership, operational and research and development structures at a senior level

✔ Absence of defined career pathways, can lead to lack in clarify of skill mix/roles and competencies needed within interdisciplinary teams

Review of current governance and accountability structures and processes in HSC Trusts

11

Operational and management arrangements of RNLDs in NI are often established within a professional accountability structure reflecting collaborative responsibilities across various healthcare professionals. Due to the interdisciplinary nature of the Learning Disability service RNLDs are more likely to work with and be operationally managed by a wider range of professionals. This may have an impact on the specific recognition of the nursing contribution of the RNLD. In addition, RNLD's have reported a disconnect from the professional workforce and a lack of clarity in professional governance and supervision arrangements.

In 2020, at the request of the of the DoH NI, the Health and Social Care Board and Public Health Agency commissioned a review to examine the effectiveness of Belfast Health & Social Care Trust's leadership, management and governance arrangements in relation to Muckamore Abbey Hospital for the five year period preceding the adult safeguarding allegations that came to light in late August 2017. A Review of Leadership & Governance at Muckamore Abbey Hospital (health-ni.gov.uk) The review team made recommendations to improve the governance and accountability arrangements in place for learning disability services, this included professional nursing governance and accountability processes. This review report should inform professional governance structures and systems for the RNLD workforce.

11.1 Survey on Current Governance and Accountability Arrangements

Analysis of a survey issued to the Executive Directors of Nursing as part of this work aimed to gather information on the current professional governance and accountability arrangements for the RNLD workforce in the 5 HSC Trusts. The results highlighted variations in processes and structures across the Trusts, and a lack of confidence about the existing clinical and professional governance and accountability arrangements. Findings from the survey included:

- All HSC Trusts employing RNLDs have a Lead Nurse for RNLD services, although one of these was noted not to be a RNLD, in addition it was unclear of the breath of this persons role or if they carried lead responsibility across directorates
- Lead Nurses with responsibility for RNLDs have different roles, levels of responsibility and pay banding across the HSC Trusts
- There is a reported lack of clarity and variation across HSC Trusts in arrangements for professional governance and accountability
- There is an under-representation of RNLD roles at senior level: with only one of the five Lead Nurses operationally managed by a Registered Nurse

Three of the five HSCTs who employ RNLDs reported that they were unsure if current processes and structure provide robust professional accountability and governance for RNLD workforce planning practice and standards of care.

11.2 Summary of Key Learning: Governance and Accountability Structures and Processes

Across the HSC Trusts arrangements for professional governance and accountability vary

All HSC Trusts have a Lead Nurse for RNLD services, although one of these was noted not to be a RNLD and the breath of their role across directorates was unclear

Lead Nurses have different roles, levels of responsibility and AfC banding across the HSC Trusts

There is an under-representation of RNLD roles at senior level: with only one of the five Lead Nurses operationally managed by a Registered Nurse

Three of the five HSC Trusts who employ RNLDs reported that they were unsure if current processes and structures provide robust professional accountability and governance for RNLD workforce planning, practice and standards of care

Evidence Base for a Practice Model for RNLDs

12

Based on the evidence gathered as part of this review the following principles should underpin the proposed model.

Figure 25: Principles underpinning proposed model

Evidence Base for a Practice Model for RNLDs

R — **Population Focus**
A sustainable workforce model to meet the health and social care needs across the lifespan is required for an estimated 2% of the population now and in the future. This should reflect a public health approach to physical, mental health and social care issues.

N — **Continuity Focus**
Continuity of care is fundamental to ensuring the delivery of safe effective care for people with a learning disability. RNLD's often play a critical role as the clinician that knows the person and their history, in coordinating and progressing clinical care smoothly as the patient moves between different parts of the health and social care system.

L — **Outcome Focus**
RNLD impact as part of the interdisciplinary team will focus on outcomes for the population and the person with a learning disability across their life span. This will require a shift from 'activity' measures to accountability through nursing frameworks.

D — **Citizen Focus**
The RNLD model will be underpinned by key principles that promote partnership working, policy direction and relevant human rights legislation. Person centred nursing practice will reflect what makes each person unique, what matters to them and putting their needs first.

S — **Learning Focus**
The model will reflect learning from the Muckamore Abbey Inquiry and other evidence-based practice and learning reports, including reports from Northern Ireland Public Services Ombudsman and feedback on the experience of people with a learning disability, their loved ones and staff. A continuous improvement focus is crucial to ensure lessons are learnt and reflected in transformation for sustainable nursing models.

12.1 Population Focus

The intervention of RNLDs should align with the latest National Institute for Health and Care Excellence (NICE) guidelines, along with other evidence-based best practices guidance. This approach ensures that interventions are based on up-to-date, reliable information, promoting a population health focus for people with learning disabilities.

Workforce planning should consider projections in the number of children with a learning disability with a focus on physical and mental health issues and ongoing health inequities for the population with a learning disability. Consideration of how best to provide accessible care to 'hard to reach' or more marginalised groups/those with multiple disadvantages e.g social deprivation, including those who come in contact with prison healthcare. Moreover, RNLDs structures must facilitate effective collaboration with all health and social services, addressing the barriers that exist: this includes challenges of transition between services/settings; especially moving from children to adult services. The model of workforce planning should promote public health through person centred, proactive health improvement, prevention and whole-family approaches.

12.2 Continuity Focus

Continuity of care is fundamental to ensuring the delivery of safe effective care for people with a learning disability. RNLD's play a critical role, as the clinician that knows the person and their history, in coordinating and progressing clinical care smoothly as the patient moves between different parts of the health and social care system. RNLD should when necessary support people with a learning disability to access specialist health and social care and intensive support in the community (NHS E 2015). RNLDs with the right skills, working with the interdisciplinary team, can provide this care, primarily in the community setting working with primary care and collaborating with outpatient and inpatient general hospital services (including mental health).

In keeping with best practice guidance and policy direction, focusing RNLD roles to a more enhanced community focused model of care will require a change in how the needs of people with a learning disability have traditionally been viewed and met. To avoid the continuation of institutional and in some cases harmful responses to presenting need, the approach of assessment and treatment in the community where possible should be adopted, with hospital admission only where necessary. The potential risk and associated harm of delay in discharge should be considered as part of the overall risk/benefit consideration to admit for inpatient assessment and treatment. In addition, continuity of care is essential to ensure effective transition between all services, with particular focus on seamless transfer from children to adult services.

12.3 Outcome Focus

Demonstrating the impact of RNLD interventions and outcomes throughout the lifespan is essential in developing a comprehensive workforce model - providing insights into how RNLDs contribute to the well-being of people with learning disabilities at different life stages. This will require a shift from the current focus which largely measures RNLD intervention as 'activity' levels.

Within the new model, RNLDs will be required to integrate appropriate validated outcome measures, into their person centred; assessments, care plans, interventions, and evaluations.

By integrating the RNLD role into specific services, either through liaison or working as part of a community or inpatient team, it is envisaged there will be:

- increased capacity of services to meet the nursing needs of people with learning disabilities across the lifespan
- effective collaborative working across teams and structures. (including challenges presented around transition between services)
- biopsychosocial assessments and interventions and healthcare monitoring at critical intervals within the person's healthcare journey to support people with a Learning Disability to live fulfilled lives in line with best practice guidance
- acute RNLD service interventions to meet the complex and intensive needs (including assessment and treatment) across all sectors
- support for people to live in their own homes and reduce the need for admission to hospital settings
- equity for people with learning disabilities through access to
  - the same services (enhanced where needed) and outcomes as other members of the public
- support for the wider interdisciplinary team and general nursing across all fields of practice, staff through education and professional practice support
- nurse led clinical and advanced practice within learning disability services

12.4 Citizen Focus

This model is underpinned by principles outlined in Equal Lives (as the current policy direction), and other strategic frameworks and legislation which upholds the human rights of people with a Learning Disability. The following principles are upheld in the proposed RNLD practice model:

- Promoting social inclusion, empowerment, and individualised person-centred support
- The Human Rights Act (1998): recognising that all human beings have value and should be treated equally
- Actively involve people with a learning disability in all decisions that affect them
- Person centred nursing practice to reflect what makes each person unique, taking into consideration the persons strengths and needs -doing everything you can to put their needs first, reflecting what matters to them – across primary, secondary and specialist learning disability service accessed at: https://www.health-ni.gov.uk/publications/nmtg-vision-leaflet
- Disability discrimination legislation compliant - ensuring reasonable adjustments provided contribute to equity of access and equity of outcome from health and social care services

Access to social care services is critical for people with a learning disability to enable them to live fulfilled lives within their community and to support families and unpaid carers. Through working in partnership with people with a learning disability and their families, and in collaboration with social care colleagues, RNLDs will provide a facilitative role, to ensure utilisation of appropriate services that facilitate people with a learning disability to live fulfilled lives within their communities (NICE 2018).

12.5 Learning Focus

The Development Group were keen to consider opportunities to inform the model through learning from analysis of learning reports and recorded adverse and serious adverse incidents experienced by people with a learning disability. Focusing on continuous improvement is crucial to ensure lessons are learnt to enable transformation and sustainable safe and effective nursing models.

12.5.1 Adverse Incidents

Within NI there is limited published detail on the adverse harm experiences of people with learning disabilities in general healthcare. Two recent publicised reports relate to the death of a child with learning disabilities and autism follow surgery in a NI hospital in 2015 (https://www.bbc.co.uk/news/uk-northern-ireland-44598982) and the death of a man with Down Syndrome and dementia in another hospital in 2016. Both reports highlight major omissions in the care provided that did or may have contributed to the premature death of both people.

A summary of the key findings include:

- Failure to provide reasonable adjustments to support the abilities and needs of people with learning disabilities
- Failure to follow prescribed care in relation to nutrition and feeding
- Lack of reasonable adjustments and failure to follow GAIN (2010) Guidelines on caring for people with learning disabilities in general hospitals
- Lack of effective interdisciplinary working within and between services
- Ineffective planning of transition from children to adult services
- Failure to report over prescribing of IV Paracetamol
- Lack of openness with family members about limitations in care provided and poor management of complaints
  Northern Ireland Public Services Ombudsman: Investigation of a complaint against the Belfast Health and Social Care Trust (July 2020) - PHSO investigations - Patient Safety Learning - the hub (pslhub.org)

It is possible there are important lessons to be learnt from a detailed analysis of SAIs in NI however the current system does not facilitate search and analysis for ongoing learning and improvement for the healthcare system and the impact on the learning disability population. Future models must focus on learning for improvement to ensure that action is taken in respect of adverse incidents and learning reports regionally, nationally and internationally.

12.5.2 Early learning from Muckamore Abbey Hospital Public Inquiry

The development of the model was informed by the early learning emerging from the MAH inquiry. In September 2023, the Inquiry panel identified early themes, based on evidence provided by patients and their loved ones, for further exploration including:

- Co-production (working with families and carers)
- Welfare activities, occupation, stimulation, and skill teaching
- Nutrition
- Sedation
- Medication, prescriptions and administration
- Dental care and hygiene
- Patient supervision
- Restraint and seclusion
- Discharge and Resettlement

(Chairs Statement, MAH Inquiry 2023)

The proposed model reinforces the importance of RNLDs in providing person-centred care, through working in partnership with people with a Learning Disability and those closest to them to reflect and to act on what 'matters to them'. The model strengthens the focus on person centred care across the lifespan, through the embracing of a biopsychosocial approach to assessment and treatment across all 'activities of living' for the person with a learning disability, delivered through 4 practice pillars of practice outlined in detail at section 13.

RNLD Model:
Right Care, Right Time, Right Place, Right Person

13

Continuity of care is fundamental to the delivery of safe effective care for people with a learning disability. RNLD's, play a critical role as the clinician who knows the person and their history in ensuring continuity of care and in particular continuity of relationship between the person, their family, carers and those important to them, and the wider HSC system.

The Royal College of General Practice (2021) describe Continuity of Care (CoC) as the extent to which a person experiences an ongoing relationship with a clinical team, or member of a clinical team. It means coordinated clinical care, that progresses smoothly as the patient moves between different parts of the health service.

It can consist of relational continuity - seeing the same people or team, management continuity – management and coordination of care and informational continuity – continuity of patient records and information.

In the proposed RNLD model, the majority of care for people with a learning disability will be provided in general healthcare services, like the rest of the population. Where required, RNLDs support should be available as part of these services, to ensure equitable access and outcomes are realised.

The proposed model promotes a suitably resourced and skilled RNLD workforce, working as part of the interdisciplinary team, to enable person centred, evidence-based continuity of care across the lifespan for people living with a learning disability.

RNLDs need to be employed in roles that maximise their impact and provide clarity of purpose within interdisciplinary teams. Focusing on numbers of staff alone, will not address the challenges experienced by people with a learning disability in achieving equitable healthcare access and outcomes. RNLDs workforce models must address the capability and capacity of staff across the range of roles within a workforce structure; empowering them, within their sphere of practice, to deliver safe and compassionate nursing care with optimum outcomes.

Given that the majority of people with a learning disability (over 99%) live in the community, it is projected that the RNLD workforce model should reflect this.

RNLDs will work across both inpatient and community settings providing:

- person centred assessment, diagnosis and therapeutic intervention
- comprehensive physical, mental health and neurodevelopmental assessment, treatment and intervention
- guidance and support, including ensuring reasonable adjustments in transition between organisational structures/services, to address the existing barriers for people with learning disabilities to improving their health
- education for other health care staff on interventions to meet the physical and mental health needs of people with a learning disability and those closest to them

Additionally, RNLDs have expertise and skills that are often used to identify and support the population of people with developmental needs.

Figure 26 below provides a diagrammatical presentation of the proposed RNLD Model which presents the 4 key areas of focus:

Figure 26: RNLD Model

Right Care

Practice Pillars: Registered Nursing Learning Disability

In the proposed model, the RNLD workforce skills and expertise will be maximised to ensure Continuity of Care across the lifespan ensuring reasonable adjustments for the person with a learning disability, focusing on the four pillars of practice:

Right Care:

RNLDs will provide evidence-based, person-centred care across the lifespan using a biopsychosocial model to:

- promote wellness and prevent ill health,
- support self-management, anticipatory care and early intervention,
- respond to deterioration and acute needs,
- monitoring and treat long-term conditions including palliative and end of life care.

Key outcome: People with a learning disability will experience evidence-based care enabling equity of outcome.

PILLAR 1

Promoting wellness and prevention of ill health

People living with a learning disability have the right to access preventative health and social care, thus nurturing health, mind and soul to live as healthily and well as possible. RNLDs have significant contribution in a liaison or specialist role promoting wellness and prevention of physical, mental and social well-being decline.

PILLAR 2

Support self-management, anticipatory care and early intervention

Person-centred care plans should identify potential physical, mental and social issues in advance of someone becoming unwell and secondary prevention (targeting those at risk). RNLD expertise can enable timely health screening, reflecting individual's wishes to enable early identification and agreed interventions that will maintain wellness.

PILLAR 3

Respond to deterioration and acute needs

If people living with a learning disability become unwell with physical or mental health issues, they should have access to timely assessment, treatment and interventions. Nurses working in primary, community, secondary care and acute hospital settings can respond to physical and mental health deterioration, supported as required by RNLDs either in a liaison or specialist role.

PILLAR 4

Provide monitoring, assessment and treatment of long-term conditions including palliative and end of life care

The patterns of physical and mental health needs and morbidity for people with learning disabilities reflect a wide range of conditions, many of which could be prevented and/or effectively managed Nurses in other services and RNLDs working in a liaison or specialist role as part of the interdisciplinary team can enable ongoing assessment, monitoring and treatment of long-term conditions including physical, metal health palliative and end of life care.

Key outcome:
People with a learning disability will experience evidence-based care enabling equity of outcome.

Right Time:

People with learning disabilities are more prone to co-morbidities and a wide range of additional physical and mental health problems when compared with the rest of the population. RNLDs will be accessible as part of the interdisciplinary team in a timely and proactive manner to:

- monitor health and wellbeing as required
- facilitate access to assessment, diagnosis and treatment (where indicated) ensuring reasonable adjustments and reducing the risk of diagnostic overshadowing (scheduled and unscheduled)
- co-ordinate, progress and/or navigate clinical care smoothly as the patient moves between different parts of the health and social care system across the lifespan

Key outcome: People with a learning disability will experience timely intervention and co-ordinated care, involving RNLDs when required.

Right Person/Skills:

RNLDs will have appropriate skills, knowledge and behaviours, and working within their scope and sphere of practice and role, will support people with a learning disability to access services in the same way as the rest of the population. Undergraduate and postgraduate education will enable professional competencies and expertise which are transferable across:

- Clinical roles
- Operational roles
- Education and Clinical Academic Roles

Key outcome: People with a learning disability will receive evidence-based interventions from clinicians with appropriate skills and level of expertise, working as part of the wider interdisciplinary team.

Right Place:

RNLDs will work across the HSC system to support people with a learning disability access services in the same way as the rest of the population, and to deliver specialist learning disability services. To ensure expertise at every point within the health and social care system RNLDs will be available in:

- Community settings including Primary Care
- Secondary and Hospital Care settings
- Specialist Learning Disability Services
- Supportive/navigation roles, such as liaison roles [see Figure 27]

Key outcome: People with a learning disability will receive assessment and where indicated intervention from an RNLD in an environment most appropriate to meet their needs.

Figure 27: Range of settings where RNLDs will be employed

> Collaborative systems of care between general and specialist Learning Disability services may require RNLDs to be embedded within a range of services where their expertise has greatest impact and improves health outcomes for the person with a learning disability

> Services delivered at both an inpatient and outpatient basis - scheduled or unscheduled. All services are accessed on basis of presenting clinical needs.
>
> *RNLDs should be embedded within these services

> RNLD liasion to some of primary and community care services.
>
> Case load holder at Primary Care/Community Care level with responsibility for accessing, planning, implementing and evaluating care and treatments using a biopsychosocial model.

Equal Lives — Citizenship — Social Inclusion — Individual Support — Empowerment — Working Together

Person with a Learning Disability and their families

Within these areas RNLDs may have some of the following roles:
▸ Registered Nurse Learning Disabilities
▸ Specialist Practice Nurse
▸ Advanced Nurse Practitioner
▸ Specialist Practice Community Nurse
▸ RNLD Consultant Nurses

Workforce Planning for a new RNLD Model

14

14.1 Primary and Community Specialist and Enhanced Support

The proposed future model for RNLD's working across the HSC recommends a significant change in how RNLD's work to meet the health and social care needs of people with a learning disability. The model places care closest to the individual with a learning disability and promotes access to existing health and social care services. This means that RNLD's can support continuity of care and will work across and be integrated into a wider range of Health and Social Care Services particularly through liaison, specialist and enhanced roles. In addition, there is currently a review of the wider service model being undertaken. This makes it difficult to compare the existing model and associated roles with a future state however some assumptions have been made as follows**.**

14.1.1 Primary and Community Care Services across the lifespan (including prison health care)

Access to general services, making reasonable adjustments where necessary whilst placing the person with a learning disability and their family/carer(s) at the centre should always be the starting point.

> **RNLD liasion to some of primary and community care services.**
>
> **Case load holder at Primary Care/ Community Care level with responsibility for accessing, planning, implementing and evaluating care and treatments using a biopsychosocial model.**

In line with strategic direction Health and Wellbeing - Delivering Together (DoH, 2016) the proposed model is designed so that care and support can be delivered close to people's homes and communities. Access to RNLD specialist health and care should be available in Primary Care both as the main entry point to Health and Social Care and the interface between associated services.

RNLD's working in primary and community care settings will seek to improve health through primary prevention, early intervention, secondary prevention (targeting those at risk) and tertiary prevention (supporting those who develop conditions to prevent recurrence or the occurrence of comorbidities). They will do this through support to both the person with a learning disability and their family/carer(s) in navigating general health, social and community services. They will also support the professionals within these settings through their specialist knowledge and skills.

RNLDs in primary and community care (including prison healthcare) will be a case load holder for the relevant period of time, providing responsive and timely evidence-based assessment and treatment. This will require RNLD's to have modest caseloads to undertake targeted and specific time limited pieces of therapeutic work with clear outcomes.

Within this context the RNLD will be delivering specialist health and care support across General Practices within Local Commissioning Areas (LCAs) and Integrated Care Services as they develop in the future.

It is assumed that there will be a significant increase in the number of RNLD's working in both community liaison roles and case holder roles at primary and community care level. This is based on a number of factors including a policy shift from hospital based to community-based care and individuals with complex physical health needs accessing advanced treatment options in the community; health needs being supported by better treatment options. To estimate the potential demand for this service, the size of the learning disability population within LCAs could be calculated based on the assumption that 2% of the population have a learning disability as illustrated in Figure 29.

Figure 28: Estimated learning disability population by Local Commissioning Areas - General Practice List Size

Local Commissioning Area	Number of Practices	Number of registered patients	Estimated LD population (2%)
Belfast	75	446,786	8,936
Northern	72	485,268	9,705
South Eastern	51	358,394	7,168
Southern	69	419,176	8,384
Western	47	337,854	6,757
Grand Total	**314**	**2,047,478**	**40,950**

Source: Portal | GP Practice List Sizes (opendatani.gov.uk)

Although a general estimate of potential learning disability population demand can be performed, without a reconfigured interdisciplinary service model, or a similar, replica, RNLD primary/community care model to benchmark against, there are limits in the ability to workforce plan as outlined in the NHS Six Step model methodology.

14.1.2 Secondary and Hospital Care across the lifespan

New RNLD roles have evolved to support individuals with a learning disability accessing scheduled and unscheduled care such as presenting in emergency departments and ongoing support throughout their acute hospital journey. e.g. the Acute Liaison Disability nursing role (RCN Connecting for Change: for the future of learning disability nursing 2021).

> **Services delivered at both an inpatient and outpatient basis and can be scheduled or unscheduled. All services are accessed on basis of presenting clinical needs.**
>
> *Where RNLDs should be embedded within services.

At present this is not universally available across acute hospitals in NI. Given the evidence base to support the need for acute liaison roles for people with a learning disability and that this is a new role in NI, it is assumed that there will be a significant increase in the number of RNLD's working in acute liaison roles.

NI is now in the unique position to set an agreed standard to ensure regional consistency in this regard.

NI Policy and best practice guidance recommends that people with a learning disability should access high-quality assessment and treatment on both outpatient and inpatient basis in the same way as the rest of the population in NI. Specialist assessment and treatment should be undertaken in the community where possible and only in hospital where necessary, with admission to hospital for the shortest possible period to prevent harm and deconditioning. Admission to hospital will usually be on a planned basis, after all assessment and treatment options in the community have been exhausted. The potential risks associated with the person's discharge being delayed should be considered as part of the overall risk/benefit analysis when considering the need to admit to inpatient care. If the potential risks of the person becoming delayed in their discharge from hospital outweighs the benefits to admission, the admission should not proceed. Inpatient assessment and treatment should never be used for any purpose other than assessment and/or treatment of mental health needs/complex behaviour that may be related to mental health.

When the mental health and/or treatment needs of a person with a learning disability needs cannot be met in the community, they should to be able to access high-quality inpatient assessment and treatment with expertise in meeting the mental health needs of people with a learning disability. In keeping with policy direction as outlined in the Bamford vision and best practice guidance, people with a learning disability should have their mental health needs met by existing mental health services, where appropriate, or by mental health services specialist in meeting the mental health needs of people with a learning disability. This may mean that learning disabilities nursing expertise will need to be available and embedded within existing mental health services to ensure the mental health needs of people with a learning disability can be met within existing mental health services.

In July 2023, the DoH set June 2024 as the planned closure date for MAH. This announcement was made following a public consultation on the future of the hospital. This means there will be a further reduction in the number of specialist learning disability inpatient beds in NI. This is likely to mean that patients requiring inpatient assessment and treatment are those most acutely unwell and are likely to have a very different set of presenting needs to that of patients currently in inpatient care whom are delayed in their discharge from hospital. This will need to be factored into future workforce planning for inpatient care and an assumption has been made that future specialist inpatient learning disability assessment and treatment will require a higher nurse to patient ratio.

It has therefore been assumed that whilst there will be a reduction in specialist learning disability inpatient beds, there is likely to be an increased need for RNLD expertise across both specialist learning disability and mental health inpatient services. Within this model, there is an assumption that RNLDs could be located in mental health acute assessment and treatment services or provide a liaison role.

Delivering Care (2019), the Policy Framework for Nursing and Midwifery Workforce Planning in NI has been paused in respect to Phase 9A, inpatients for Learning Disability, and the needs of people with a learning disability in mental health services was not factored into the delivering care phases for mental health services (phase 5a or 5b).

14.1.3 Student Nurse profile of the future
Uptake of RNLD pre-registration has been falling year on year. It is essential that for the field of nursing the DoH consider ways to increase and retain RNLD pre-registration students. This should include scoping opportunities to promote RNLD as a career opportunity of choice and widening access to RNLD pre-registration education and training.

Engagement and Communication on Proposed Model

15

Throughout the development of this future model for RNLD Nursing, a comprehensive programme of engagement was facilitated with people with a Learning Disability, those closest to them, and staff across a wide range key stakeholders. There were particular challenges in engaging with people with a Learning Disability, and therefore the feedback on the proposed model was primarily provided by families and carers on behalf of their loved ones.

Feedback and comments on the proposed RNLD workforce model clearly indicated support. A summary of comments and feedback are included at Figure 29 below. See Appendix 7 for communication and engagement summary.

Figure 29: Feedback and comments from staff and those close to people with a learning disability

Great to see RNLDs getting back to what we were trained to do.

Very exciting times ahead for not only RNLDs but much needed changes for our population of people with learning disabilities, to address their health needs. Really look forward to see this being rolled out.

Great for all levels of nurses to be involved and assist as change agents as we move forward with learning disability nursing.

STAFF

When a person no longer has family to support them the role of the RNLD can become even more key as an advocate and support to access appropriate services.

PEOPLE WITH A LEARNING DISABILITY / THOSE CLOSE TO THEM

This is what we want to meet the needs of our daughter.

This is what is needed to make services more equitable.

16

Governance and accountability arrangements to ensure ongoing professional nursing leadership for the RNLD Workforce Model

Nurses and midwives in NI perform their roles in a wide range of hospital and community settings and in a wide range of teams both uni and interdisciplinary, statutory and in partnership with the independent and third sectors. HSC Trusts are large complex organisations which can make the process of professional governance, assurance and accountability challenging.

In order to respond effectively to the needs those who have a learning disability and deliver sustainable improved outcomes, we need professional governance to be provided through senior leadership roles within our HSC Trusts. Those in leadership and accountability positions need an in-depth knowledge of population health needs and understanding how learning disability nurses can be strategically utilised across all interdiscplinary teams.

In addition, there needs to be assurance that the governance framework is utilised effectively to enable the Executive Director of Nursing to provide assurances to their Chief Executive and Trust Board about the quality of nursing care both provided for and commissioned by that Trust. Learning disability nursing needs to have equitable recognition within the organisation professional governance structures and systems, including effective processes of professional accountability across interdiscplinary teams and operational directorates where RNLDs often work.

Performance management processes need to evidence professional and service performance standards through individual and team quality measures, by moving to an outcome focused model. These measures should be in line with evidence-based interventions across the lifespan for people with learning disabilities. Established quality measures should consider how equity of access and outcomes of nursing care is achieved for people with learning disabilities across the 4 pillars outlined in section 13.1.

In 2023, the DoH CNO commissioned NIPEC to lead a programme of work to review and strengthen the regional assurance system for nursing and midwifery professions in NI. It is crucial that RNLD professional assurance systems/structures are aligned to this work. The establishment of a regional quality excellence framework should promote professional accountability of RNLD services and support the transformation and development of the RNLD workforce.

17

RNLD Communities of Practice

Providing effective engagement processes and structures across the profession of nursing is crucial in communicating and informing the strategic direction and enabling the voice of the registrant to be heard.

The NI Learning Disability Nursing Strategic Workforce Development Group asked the RNLD Expert Reference Group to establish a regional RNLD Communities of Practice (CoP) to support collaboration and engagement. The RNLD CoP is now established and is open to all RNLDs and other RNs who have an interest in providing nursing services to people with learning disabilities. The RNLD CoP is co-chaired by two senior RNLDs. It meets quarterly and reports directly to the RNLD Expert Reference Group. The RNLD CoP held its first event on 28th April 2023 (Appendix 3) outlines the Terms of Reference of the CoP.

Recommendations

18

In May 2023, the CNO for NI launched the Vision for the professions of Nursing and Midwifery. This included strengthening the focus on four strategic areas of work:

- Workforce/Workload Planning
- Education and Training
- Quality Assurance framework
- Career Pathways

The recommendations below aim to align to the CNO vision for the future of the professions in NI and establish a sustainable model for RNLD nursing which will provide: the right staff, with the right skills, in the right place based on local population learning disability healthcare.
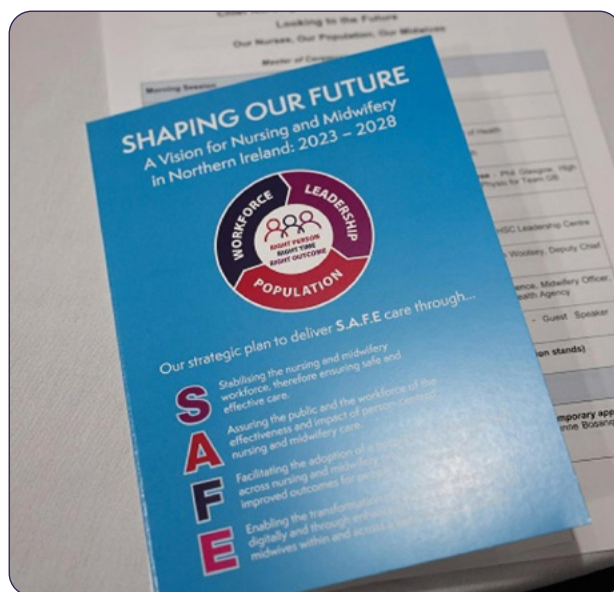
1. Workforce/Workload Planning
(aligned to the delivering care policy framework)

Workforce/workload Planning

Support on-going evidence-based workforce planning that ensures the availability of a suitably skilled and resourced registrant workforce.

1. Establish workforce models that support RNLD employment in areas that support continuity of care in: acute and community liaison roles and where relevant in general and specialist services e.g mental health

2. Agree future RNLD roles across the 4 pillars of care and treatment outlined within the proposed model, that lead to evidence-based, person-centred positive outcomes for the health and well-being of people with a learning disability across their life span

3. Establish robust arrangements to collect data that provides and accurate information on the number, abilities and health needs of people with a learning disability in NI to inform workforce planning and workload allocation

4. Implement a phased plan to remove all 'parallel' or 'alternative' services provided by RNLDs/CNLDs that require people with a learning disability to follow a different pathway to access general services and do not provide equity of access/outcomes

5. Establish robust arrangements to collect and analyse data on the roles, age profile and workplaces including employment destination/s of RNLDs in Northern Ireland

6. Proactively recruit RNLDs into funded RNLD specified posts to ensure the right people with the right skills are providing the right care in the right place

7. Develop systems to facilitate all health and social care staff to access RNLDs for advice and support when designing and implementing reasonable adjustments to support equitable healthcare provision for people with a learning disability

8. Ensure all proposed service developments involving RNLDs clearly relate to DoH strategic nursing priorities, consistent with the service principles with Equal Lives (DHSSPS, 2005) and developed with oversight of the Director of Nursing

9. Develop processes to ensure all registered nurses working in mainstream and specialist services have access and opportunities to acquire the required knowledge to care for a person with a learning disability

2. Education and Training

Education and Training

Ensure RNLDs have equitable access to post graduate education to support the delivery of safe and effective person-centred care, and RNLD professional development throughout their career.

1. Ensure through the education commissioning process RNLDs have access to a range of education programmes that supports the delivery of safe effective care, provides professional development and enables transformation of services

2. Provide post registration education and skills development required to ensure RNLDs use language within all nursing assessments, person centred care plans and evaluations that demonstrates outcomes focused approach to interventions

3. Review models of RNLD pre-registration education and provision to incorporate a range of hybrid learning approaches and opportunities for return to practice

4. Establish education programmes to support conversion from other fields of practice

5. Review and support access to practice learning experiences, including non-traditional settings that reflect the future RNLD role through effective collaboration of HSC Trusts, independent Provider Organisations and Higher Education Institutions (HEIs)

6. Develop processes to ensure all registered nurses working in general and specialist services across settings have access and opportunities to acquire the required knowledge and skills to care for a person with a learning disability

7. Develop a Northern Ireland marketing campaign to raise awareness and profile of nursing careers in Learning Disabilities

8. Explore opportunities and challenges to widen access to pre-registration learning disability programmes for existing health and social care workforce e.g. Band 2-4 staff

3. Quality Assurance framework

Quality Assurance Framework
Establish structures and processes that provide robust governance, professional leadership, accountability and quality assurance for RNLD services and demonstrate impact on outcomes for people who have a learning disability.

1. Establish a regional governance model to ensure professional supervision and support that enables person centred care and compassionate workplace cultures where RNLDs can thrive

2. Undertake an in-depth analysis of all reports of adverse and serious adverse incidents involving people with a learning disability within HSC Trusts or services commissioned by HSC Trusts in Northern Ireland

3. Employ systems to capture information about the healthcare experience of people with a learning disability to inform learning and improvement

4. Establish robust arrangements to collect data that identifies the impact of all population health outcomes for people with a learning disability

5. Develop outcome focused assurance systems that demonstrate the impact of evidence-based nursing assessment e.g. long-term conditions and co-morbidities, avoidable hospital admissions, harm and avoidable harm/deaths

6. Develop a dashboard for assurance and improvement related to quintuple aim indicators: workforce, safety/quality, experience, equity, value for money and population health

4. Career pathways

Career Pathways

Ensure career pathways enable RNLDs to develop the necessary knowledge, skills, confidence and leadership required to enable people with a learning disability to have equity of access and outcomes from RNLDs working in primary and community, secondary and hospital care and structures.

1. Develop a RNLD career pathway taking into consideration the future model for RNLD services that provide regionally agreed job titles, job descriptions, bandings for all RNLD posts across HSC Trusts in Northern Ireland (endorsed by Directors of Nursing)

2. Develop career pathways to enable RNLDs to access leadership positions and deliver person centred care and expertise across the 4 pillars of practice across the life span for a person with learning disability as outlined in the RNLD model

3. Develop and embed a regionally agreed preceptorship supporting transition to employment, complemented with a learning and development framework to provide the range of competencies and proficiencies required for rewarding career across: clinical practice, operational roles and research and development

4. Ensure the career pathway incorporates development needs of staff working in Band 2-4 roles

Conclusion

19

This paper has outlined significant challenges in meeting the population needs of those who have a learning disability in Northern Ireland.

It proposes a future model to maximise the RNLD input and impact towards recognising the abilities and meeting the health and care needs of people with a learning disability across Northern Ireland (NI).

The RNLD Strategic Development Project Group present this report to the Chief Nursing Officer in the DoH to take forward the recommendations, in order to establish a new model for RNLD nursing to meet the learning disability population current needs and provide a sustainable model for the future.

Abbreviations

ADoN	Assistant Director of Nursing
ADHD	Attention Deficit Hyperactivity Disorder
AfC	Agenda for Change
ANP	Advanced Nurse Practitioner
BHSCT	Belfast health and Social Care Trust
CAMHS	Child and Adolescent Mental Health Service
CEC	Clinical Education Centre
CNLD	Community Nurse Learning Disability
COC	Continuity of Care
CoP	Communities of Practice
CNO	Chief Nursing Officer
CPD	Continuous Professional Development
DHSSPS	Department of Health Social Services and Public Safety
DoH	Department of Health
EDoN	Executive Director of Nursing
GAIN	Guidelines and Audit Implementation Network
GEMS	Graduate Entry Masters
HC	Head Count
HEIs	Higher Education Institutions
HSCT	Health Social Care Trusts
IDSTILDA	The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing
IDT	Inter-disciplinary Team
LeDeR	Learning from lives and deaths
MAH	Muckamore Abbey Hospital

MECC	Making Every Contact Count
NHSCT	Northern Health and Social Care Trust
NICE	National Institute for Clinical Excellence
NI	Northern Ireland
NIPEC	Northern Ireland Practice and Education Council for Nursing and Midwifery
NMC	Nursing and Midwifery Council
NMTG	Nursing and Midwifery Task Group
OU	Open University
PHA	Public Health Agency
PSNI	Police Service Northern Ireland
QUB	Queens University Belfast
RCN	Royal College of Nursing
RNLD	Registered Nurse Learning Disabilities
RN	Registered Nurse
RoI	Republic of Ireland
RQIA	Regulation Quality Improvement Authority
SAI	Serious Adverse Incidents
SEHSCT	South Eastern Health and Social Care Trust
SHSCT	Southern Health and Social Care Trust
SPO	Senior Professional Officer
SPPG	Strategic Planning and Performance Group
SPQ	Specialist Practice Qualification
UK	United Kingdom
WHSCT	Western Health and Social Care Trust
WTE	Whole Time Equivalent

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Glossary of Terms

Continuity of Care the extent to which a person experiences an ongoing relationship with a clinical team, or member of a clinical team. It means coordinated clinical care, that progresses smoothly as the patient moves between different parts of the health service.

Designated Roles to officially give someone a particular role.

Development Group RNLD Regional Strategic Workforce Development Group

Diagnostic overshadowing the misattribution of symptoms of one illness to an already diagnosed comorbidity, leads to compromised patient care and likely contributes to increased mortality experienced by individuals with mental illness.

Evidence-based practice (EBP) provides nurses with a method to use critically appraised and scientifically proven evidence for delivering quality health care to a specific population.

Health Inequalities are unfair and avoidable differences in health across the population, and between different groups within society.

Holistic approach A holistic approach means to provide support that looks at the whole person, not just their mental health needs. The support should also consider their physical, emotional, social and spiritual wellbeing.

ICD The International Classification of Diseases (ICD) is designed to promote international comparability in the collection, processing, classification, and presentation of mortality statistics.

Integrated care also known as integrated health, coordinated care, comprehensive care, seamless care. It focuses on more coordinated and integrated forms of care provision.

Interdisciplinary: is a group of individuals from different professional backgrounds like doctors, nurses, and physiotherapists, who develop and implement a patient-centred care plan for effective healthcare delivery.

Learning Disability is defined as having the following three criteria:
* the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence)
* which started before adulthood with a lasting effect on development
* with a reduced ability to cope independently (impaired social functioning)

Source: *Equal Lives* (DHSSPS; 2005, p18)

Making Every Contact Count (MECC) is an approach to behaviour change that uses of day-to-day interactions that organisations and people have with other people to support them in making positive changes to their physical and mental health and wellbeing.

Neurodevelopment is a term referring to the brain's development of neurological pathways that influence performance or functioning.

Outcomes focused is a practice that places the individual at the centre of their care and supports plans to achieve the best possible outcome.

Performance management process includes planning, monitoring, developing, rating and rewarding employees. This is done both on a continuous basis and as part of a cyclical process.

Person Centred is about focusing care on the needs of individual. Ensuring that people's preferences, needs and values guide clinical decisions, and providing care that is respectful of and responsive to them.

Precautionary suspension is suspension mainly to mitigate further risk to an employer in instances where disciplinary action is contemplated.

Prevalence is a measure of the frequency of a disease or health condition in a population at a particular point in time.

Quality Assurance is a dynamic process through which nurses assume accountability for quality of care they provide.

Reasonable Adjustments are changes made to remove or reduce a disadvantage related to someone's disability.

Specialist Practice Qualifications (SPQ) are annotations to the NMC register. They indicate that a registered nurse has successfully undertaken an NMC approved SPQ programme that meets our standards in a particular area of practice. To undertake a specialist practice qualification, you must be a first level registered nurse.

Appendix 1

Population Prevalence Northern Ireland - Learning Disability (2023)

High-Level Position Paper

Population Prevalence Northern Ireland - Learning Disability (NI) 2023

Introduction

Determining the prevalence of Learning Disabilities in Northern Ireland was deemed important for the main 'Equity of Access and Outcome' report. However, given the presence of different sources of information on this subject area, none of which considered definitive, it was decided to produce this brief paper to provide a reasonable high-level estimate. The approach involved utilising available information, and the professional judgement of the Registered Nursing Learning Disability Steering Group.

In order to accomplish this, the following areas were addressed: clarifying the terminology and definition of a Learning Disability; and then compiling available information on population prevalence estimates to establish a reasonable high-level estimate of the Learning Disability population.

Additionally, prevalence was then briefly considered demographically by Health and Social Care Trust (HSCT) and also areas of deprivation.

It is acknowledged that without reliable and valid sources of long-term data in relation to the Learning Disability population prevalence in NI that the findings of the position paper may not be generalisable.

Terminology and Definition

The Royal College of Psychiatrist's in (2016) recognised that in the United Kingdom (UK) the terms ' learning disability' and 'learning difficulty' were often used synonymously and advised that the more recent term of 'intellectual disability' had replaced both the aforementioned terms internationally. That said, in Northern Ireland (NI) the term Learning Disability remains the designated terminology within Equal Lives (2005) and therefore for consistency will be the term used throughout the remainder of this document to describe the condition.

The following describes Learning Disability as a lifelong condition comprising of three elements:

> "Ability to understand information, to reason, learn and plan is significantly below average; Below average ability to function independently and to cope with everyday life; Started in the development period (before 18 years of age)." (Royal College of Psychiatrists 2016, p5).

The diagnostic category for individuals with a Learning Disability is outlined in the International Classification of Diseases, 11th edition (ICD-11) World Health Organisation (2022) under the heading 'disorders of intellectual development,' as one of a group of neurodevelopment disorders. This edition describes disorders of intellectual development as a group of:

> "Etiologically diverse conditions originating during the development period characterised by significantly below average intellectual functioning and adaptive behaviour two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardised tests. Where appropriately normed and standardised tests are not available diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators." (World Health Organisation 2022: ICD-11 for Mortality and Morbidity Statistics (who.int))

Learning Disability Population Prevalence Estimates
Epidemiological data for Learning Disability prevalence has been found to be lacking, in part, because responsibilities for services can be spread over different agencies and, or, may be embedded in other fields such as Mental Health or Disabilities (Mercier et al 2008).

The global estimate of individuals with an intellectual disability in 2019 was estimated to be around 107.6 million which forms about 2% of the whole population (Nair et al 2022).

In NI to begin to ascertain population estimates of persons with Learning Disabilities data samples from existing adult services were considered. However, the samples did not appear to be entirely representative as they were lower than those previously projected in the Bamford Review (2005).

The Bamford Review (2005) referenced a study based on information formerly held by HSCTs, estimating a population of 16,365 persons with a Learning Disability, including both adults and children. Their review inferred that this number was likely an underestimate of the actual population size, as the sample consisted of individuals known to services at a point in time. Consequently, the review team suggested that the frequently cited figure of 2% was probably more accurate, particularly when individuals with milder forms of impairments were allied with poor social circumstances.

The figure of a 2% prevalence of Learning Disabilities in the general population was less than the data collated from the National Census NI, in 2011, which reported a total population of 40,177 individuals with a long term condition of Learning, Intellectual, Social or Behavioural Difficulty equating to 2.22% of the total population (NISRA 2011). However, a briefing paper to the Northern Ireland Assembly, in 2014, recognised that the census figure may have been an overestimate of the actual number of people with Learning Disabilities, as it also included those with social or behavioural difficulties in its data collection (NIAR 2014).

In a study conducted in the Republic of Ireland a notable difference between service and census data was observed. The prevalence rates recorded in their census were nearly double those obtained from their Learning Disability service database (McConkey et al 2019). Reasons suggested for this included: individuals with milder forms of Learning Disability no longer needing or wanting specialist services; a shortage of appropriate services in the individual's local area; and the inclusion in the census returns of individuals with other impairments such as Autism.

In NI there has been a recent change in how the Census Survey (NISRA 2022) captures the prevalence of individuals with a Learning Disability. A Learning Difficulty, Autism and Asperger's syndrome have been distinguished from the Learning Disability definition and are captured separately in the census. However, it's worth noting that co-occurring Learning Disabilities and Autism are not uncommon according to Dunn et al (2019). Therefore, separating them in the census may have affected the reported lower estimate of, 16,923 or 0.9% individuals in the population with a Learning Disability (NISRA 2022), compared to the previous Census in 2011 (NISRA, 2011).

In England, there has been no definitive record of the number of people with Learning Disabilities, as no government department had compiled comprehensive data on this, and it was not included in their National Census. That said an estimate of Learning Disability prevalence was derived at an estimated 1,087,100 people, in 2015. This estimate was derived from a combination of; data collected by government departments, populations projections, and findings from epidemiological research (PHE 2016). To determine the percentage of the Learning Disability population, at that time, the estimate can be divided by the entire population, which was 54, 786, 300 in 2015 (Office for National Statistics 2016). This equates to 1.98%.

The University of Ulster undertook research, funded by the Economic and Social Research Council, which centred on accessing and analysing data concerning Learning Disability in NI from 2007 and 2011. This research compared prevalence estimates for individuals with Learning Disability using data from the 2011 Census and survey data from the 2007 NI survey on Activity Limitation and Disability (NISALD.) The study found an overall prevalence rate of 1.6-2% (McBride et al 2021).

In summary the prevalence estimate for Learning Disabilities appears to be around 2%, as indicated by Nair et al (2022), from an international perspective, Bamford (2005) from a NI perspective, and close to the PHE figure of 1.98% for England in 2015 (2016). The value of 2% also falls within the range of 1.6 to 2% cited by University of Ulster research in 2021 (Bride et al 2021).

Hence, in the absence of reliable and validated data on the Learning Disability population, for this paper, the consensus reached by the Learning Disability Steering Group was to estimate a prevalence of 2% for Learning Disabilities until further data becomes available.

Estimated Learning Disability Population Prevalence by Health and Social Care Trust NI
On census day, 21st March 2021, the general population in Northern Ireland was reported as 1,903,175 (NISRA 2022) and in January 2023, the total General Practice (GP) List Size reached 2,033,168 (DOH 2023).

The demographic split of the population by Health and Social Care Trust (HSCT) was reported in 2020 (NISRA 2020), as shown in Table 1 below. Subsequently, the percentage share of the population by Trust can be calculated, as demonstrated in the last column i.e. Percentage Share NI.

Table 1 General Population by Health and Social Care Trust 2020

HSC Trust	Population 2020	Percentage Share NI
Western HSCT	303,207	16%
Northern HSCT	480,194	25%
Southern HSCT	388,688	21%
South Eastern HSCT	364,191	19%
Belfast HSCT	359,230	19%
Total	**1,895,510**	**100%**

Source: NINIS: Northern Ireland Neighbourhood Information Service (nisra.gov.uk)

Applying the 'Percentage Share NI' column to the total GP List size figure of 2,033,168 can be calculated as outlined in the Column 3 of Table 2 below.

Learning Disability (LD) population estimates by Trust can then be derived by assuming a 2% prevalence rate among the general population as illustrated in Column 4 of Table 2, below.

Table 2: General Population and Learning Disability Population estimates by Health and Social Care Trust in 2023, based on GP List Size.

HSC trust	Percentage Share NI	General Population Estimates for Trusts in 2023, based on GP List Size.	Learning Disability (LD) Population Estimate for Trusts in 2023, assuming 2% of the general population has a LD, based on GP list size.
Western HSCT	16%	325,307	6,506
Northern HSCT	25%	508,292	10,166
Southern HSCT	21%	426,965	8,539
South Eastern HSCT	19%	386,302	7,726
Belfast HSCT	19%	386,302	7,726
Total		**2,033,168**	**40,663**

Learning Disability population estimates outlined in Column 4 of Table 2 have been used to create a bar chart, as depicted below.

This indicates that the Northern HSCT has the highest percentage of population with Learning Disabilities, followed by the Southern HSCT, the South Eastern HSCT, Belfast HSCT and Western HSCT, respectively.

Table 3 Learning Disability (LD) Population Estimate for Trusts in 2023, assuming 2% of the general population has a LD, based on GP list size.

Estimated Learning Disability (LD) Population by HSCT, based on GP list size (2023) Assuming 2% of the General Population has a LD
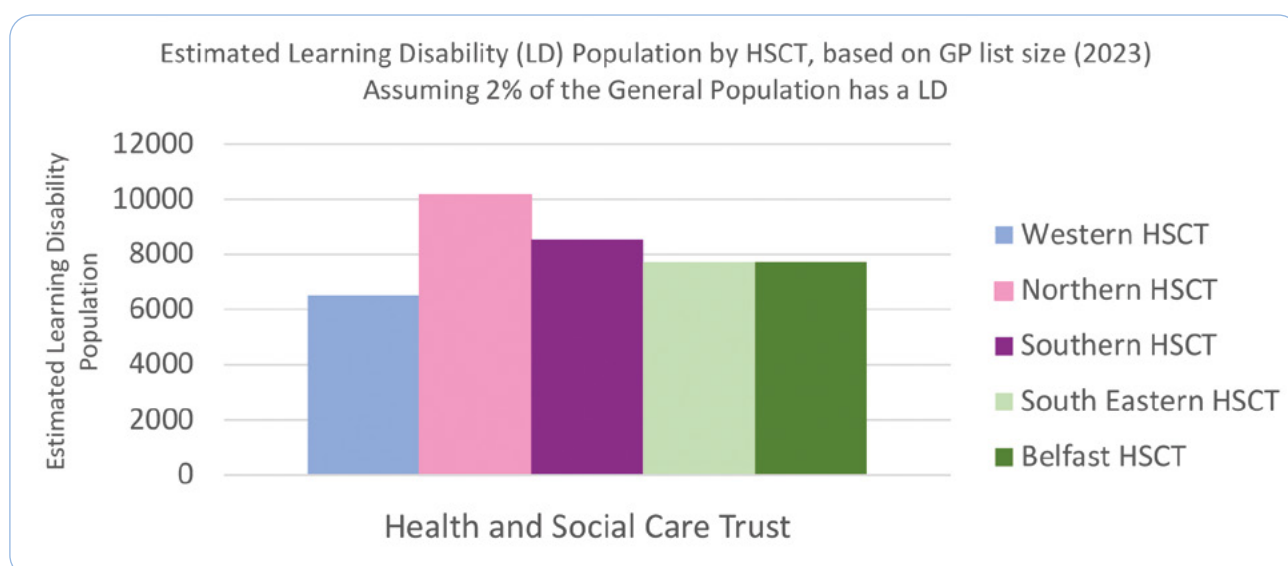
Population Health- Deprivation and Health Inequalities

As outlined in the strategic framework for NI, Making Life Better (DOH 2014) it is important to consider the broader determinants of deprivation and health inequalities for the general population when addressing population health issues related to individuals with Learning Disabilities. In Nair et al's global study of regional inequalities in the prevalence of Learning Disability (2022), highlights the need to scale services for people with Learning Disabilities according to regional disadvantage to help reduce inequalities. Otherwise, disparities in social and health outcomes may increase over time. By way of an example, Public Health England (2015, p40) c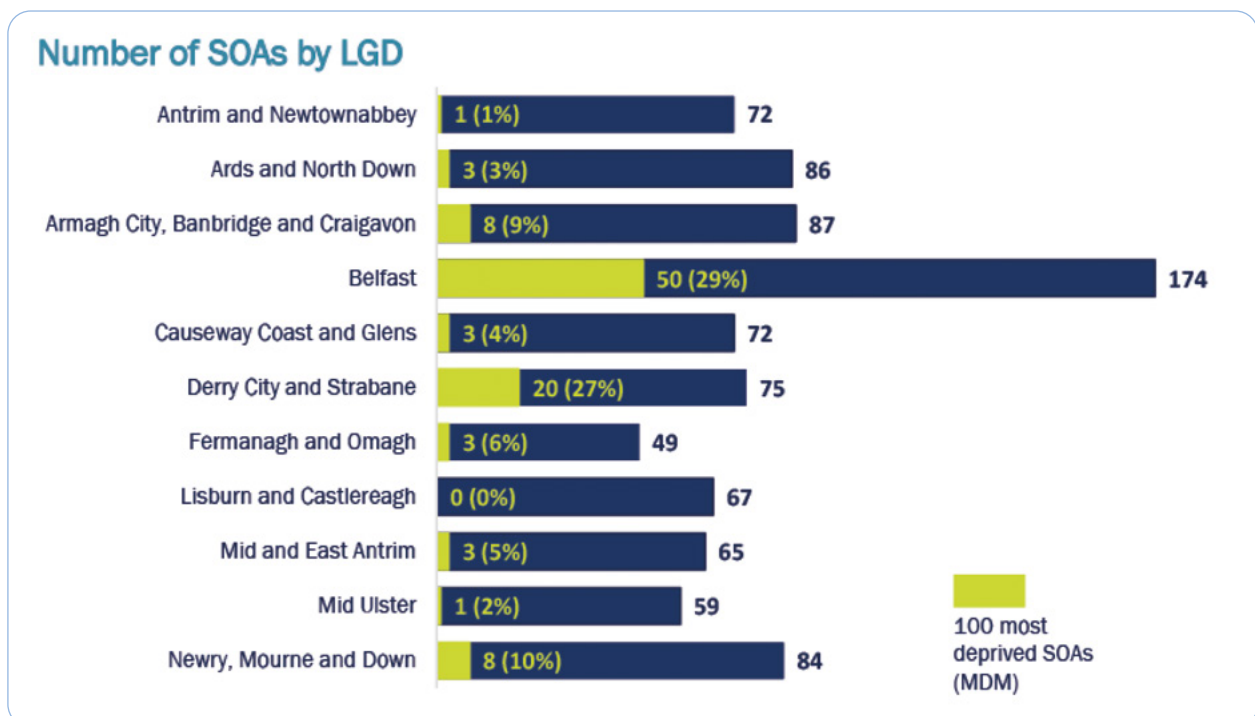ited data indicating that 'children from poorer households or who were living in more deprived neighbourhoods were more likely to have Special Educational needs associated with learning disabilities.' Therefore, being cognisant of this information can help target population health need accordingly.

To this end, a Table of the most deprived areas in Northern Ireland has been taken directly from the Northern Ireland Multiple Deprivation Measures NISRA (2017) for consideration, as illustrated below.

For noting, the Table indicates that Belfast has the highest proportion of deprivation of all Local Government Districts (LGDs), followed by Derry City and Strabane.

Table 4: Most deprived Super Output Areas by LGD (NISRA)

Number of SOAs by LGD

LGD	100 most deprived SOAs (MDM)	Total
Antrim and Newtownabbey	1 (1%)	72
Ards and North Down	3 (3%)	86
Armagh City, Banbridge and Craigavon	8 (9%)	87
Belfast	50 (29%)	174
Causeway Coast and Glens	3 (4%)	72
Derry City and Strabane	20 (27%)	75
Fermanagh and Omagh	3 (6%)	49
Lisburn and Castlereagh	0 (0%)	67
Mid and East Antrim	3 (5%)	65
Mid Ulster	1 (2%)	59
Newry, Mourne and Down	8 (10%)	84

Source: Northern Ireland Statistics and Research Agency, Northern Ireland Multiple Deprivation Measures 2017, p8.
NIMDM17- with ns.pdf (nisra.gov.uk)

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Appendix 2

Registered Nurse Learning Disabilities – Strategic Workforce Development Group

Terms of Reference

1. BACKGROUND

Over the past few decades, in response to a better understanding of how best to meet the needs of the population of people with a learning disability there has been a shift in the strategic direction and associated models of service provision. Meeting the health and social care needs of people with a learning disability in this new landscape has presented both challenges and opportunities for RNLD's.

In 2019 Chief Nursing Officer, Department of Health initiated a review of the role of the registered nursing for learning disabilities workforce in Northern Ireland. The overarching aim was to examine the current role of a Registered Nurse Learning Disabilities (RNLD) and make recommendations to support the future role within health and social care settings across Northern Ireland to enable people with a learning disability, their families and carers to be supported, to achieve and maintain good health and to live long, healthy, active and fulfilled lives.

In light of this, nursing pre and post graduate education and professional development provision needs updated to ensure new ways of working are implemented and roles developed. In doing so, RNLD's will have an important role to ensure people are enabled and supported to achieve their full health and wellbeing potential, and inequalities in health are reduced.

2. PURPOSE OF THE GROUP:

The Chief Nursing Officer commissioned NIPEC to establish a Task and Finish Group to rapidly build on previous learning. The group will define the roles that RNLDs should be delivering, in line with evidence-based practice, to meet the needs of the population in Northern Ireland. This will include the development of a proposed model to ensure the availability of a suitably skilled and resourced registrant workforce across primary, secondary and specialist health and social care service in Northern Ireland, in line with the strategic direction.

To achieve this purpose, the Group (see Annexe 1 membership) will focus on the following objectives:

• Ensure effective communication and engagement with key stakeholders about the work of the Task and Finish group, including dissemination of information within organisations and provide timely feedback.

Define the plan:
• Scope the current RNLD practice model
• Scope the health care needs of the population of individuals with a learning disability in Northern Ireland

Map the Service Change
• Identify evidence-based interventions to meet the health care needs of the population of individuals with a learning disability in Northern Ireland
• Define a best practice model for RNLDs to meet the health care needs of the population of individuals with a learning disability in Northern Ireland

Defining the Required Workforce
• Describe the role of the RNLD in the model of care (across the lifespan) that maximises the impact across all health and social care services for people with learning disabilities.
• Establish regionally agreed definitions on all roles relating to RNLDs.
• Develop a Nursing Career Framework for RNLDs, to include specialist, advanced practice, consultant nurse and clinical academic roles across specialist learning disabilities services for children, adults and older people.
• Develop, aligned to the Career Framework above, a Learning and Development Framework for RNLDs.

Understanding Workforce Availability
• Review current education commission model (pre and post registration) and make recommendations aligned to the Learning and Development Framework
• Recommend a plan for a phased approach to deliver a regional workforce model which provides: the right staff, with the right skills in the right place based on local population learning disability healthcare needs

Developing an Action Plan
• Establish a regional RNLD Community of Practice Group that will act as a source of guidance and expertise for RNLD roles.
• Consider the governance, reporting and accountability arrangements to ensure ongoing professional nursing leadership for the RNLD workforce

Implement, Monitor and Refresh
• Make recommendations regarding to on-going implementation, monitoring and evaluation of the objectives.

3. CHAIRING ARRANGEMENTS

The Task and Finish group will be Co-chaired by Suzanne Pullins, Executive Director of Nursing (NHSCT) and Linda Kelly, Chief Executive of NIPEC.

4. QUORUM

Quorate membership is 50% of the total membership number.

5. FREQUENCY OF MEETINGS

Meetings will be arranged in order to complete the activity which will be defined in an agreed work plan. A number of work streams will be established to focus on specific areas of work.

6. RECORD OF MEETINGS

NIPEC staff are responsible for agenda setting, record keeping and circulation of relevant papers in collaboration with the Co-Chairs of the Group.

7. ACCOUNTABILITY OF TASK AND FINISH GROUP

The group will report directly to the Chief Nursing Officer as per governance structure below.

NI Learning Disability Nursing - Strategic Workforce Development Group

Membership	Organisation
Chair – Suzanne Pullins	NHSCT
Co-Chair – Linda Kelly	NIPEC
Prof. Owen Barr	Ulster University
Siobhan Rogan	PHA
Siobhan Donald	PHA
Sheila Kinoulty (From Jan 23) (Gillian McCorkell up to Dec 22)	PHA
Gillian Weir (From Jan 23)	PHA
Rosaline Kelly	Royal College of Nursing
Dr Patricia McNeilly	Workforce – NMAHP, DoH
Michelle Curran	BHSCT
Seamus Coyle/Rhona Brennan	NHSCT
Barbara Tate	SEHSCT
Maureen Roberts	SHSCT
Clionagh McElhinney	WHSCT
Frances Cannon	NIPEC
Cathy McCusker	NIPEC
Wendy McGregor	RQIA

NI RNLD Expert Reference Group

Membership	Organisation
Prof Owen Barr	Professor of Nursing and Intellectual Disabilities, Ulster University, Chair
Siobhan Rogan	Assistant Director for Mental Health and Learning Disability, PHA
Frances Cannon	Associate Senior Professional Officer, NIPEC (Project Support)
Michelle Curran	Consultant Nurse Learning Disabilities, BHSCT
Michael McBride	RNLD, Children's, BHSCT
Frances Maguire	RNLD Adult, BHSCT
Barbara Tate	Trainee Consultant Nurse Learning Disabilities, SEHSCT
Julie Richie replaced Sharon Ogle	Representing RNLD Children's SEHSCT
Stephanie Price	Lead Nurse Adult SEHSCT
Maureen Roberts	Trainee Consultant Nurse Learning Disabilities, SHSCT
Donna Grant	representing RNLD Children's SHSCT
Oisin McAuley	representing RNLD Adult SHSCT
Seamus Coyle	Trainee Consultant Nurse Learning Disabilities NHSCT
Rhona Brennan	Operational Lead NHSCT
Michelle Angelone	representing RNLD Children's NHSCT
Clionagh McElhinney	Trainee Consultant Nurse Learning Disabilities, WHSCT
Janet Doherty	Head of Service Lead Nurse Adult WHSCT
Donna Milligan	Community Nurse – representing Children's WHSCT
Denise Magill replaced by Marius Coman	Triangle Housing (Dec 2023)
Rosaline Kelly	Senior Nurse Professional Practice, Royal College of Nursing
Damian McAleer	Nurse Education Consultant, Clinical Education Centre
Nicola McCann	Learning Disability Inspector, Regulation and Quality Improvement Authority
Maurice Devine	Staff Tutor Open University
Dr Lynne Marsh	Senior Lecturer, Queens University Belfast
Leslie–Anne	Newton Arc UK (circulation only)
Claire Thompson	QUB Pre-registration student

Appendix 3

TERMS OF REFERENCE (December 2022)

Registered Nurse Learning Disabilities – Expert Reference Group (RNLD ERG)

BACKGROUND

In 2014 the in response to the Strengthening the Commitment - NI Action Plan the NI Collaborative was established to take forward the actions from the NI Action Plan. In 2019 the CNOs across the UK noted their intention to stand down the four countries Strengthening the Commitment groups. This coincided with the Department of Health (DoH) decision to undertake a review of the role of registered nurses; learning disabilities workforce in Northern Ireland. By agreement with the CNO the recommendations from the review will inform the activity of the Collaborative going forward.

The 31st January 2020 marked the start of the pandemic. During the pandemic meetings and activity of the Collaborative was paused at the request of the HSC due to system pressures, scheduled meetings were impacted significantly with only two catch up-meetings during this time.

The DoH is now concluding the review of the role of the Registered Nurses Learning Disabilities workforce in Northern Ireland (pending publication) and the CNO has commissioned NIPEC to establish a Registered Nurse Learning Disabilities – Strategic Development Project Group to take forward the outworking's of the review.

In September 2022 the CNO and the CEx of NIPEC asked the Collaborative to provide a high-level overview of work of the NI Collaborative with a view to a refresh /rebrand and re-energising of the group whose primary function going forward would be to support the outworking's of the Registered Nurse Learning Disabilities – Strategic Development Project Group.

To that end the NI Collaborative members met on the 8th November 2022 to consider the membership of the new group and explore potential name changes.

There was a consensus view that the membership of the refreshed Group which aims to support Project Group must include those with the right professional expertise to inform the work and it was also agreed that the name of the group would change from the NI Collaborative to the Registered Nurse Learning Disabilities – Expert Reference Group (RNLD ERG)

Registered Nurse Learning Disabilities – Expert Reference Group (RNLD ERG)

AIM:

The RNLD ERG will act as a resource and an expert reference group for the various workstreams stemming from the Registered Nurse Learning Disabilities – Strategic Development Project Group. The RNLD ERG will:

- take responsibility for providing awareness and encouraging participation in the out workings of the Project group across all areas of nursing for people with learning disabilities
- actively contribute to the development of a Nursing Career Framework for RNLDs, to include specialist, advanced practice, consultant nurse and clinical academic roles across specialist learning disabilities services for children, adults and older people.
- provide a regional resource through the sharing of knowledge, expertise, service development, and innovation that will promote, influence and enhance best practice and consistency in nursing practice of people with learning disability within services across N. Ireland
- provide a forum to identify continuing professional development opportunities and inform the commissioning of programmes that will enhance RNLD practice aligned to the objectives of the Registered Nurse Learning Disabilities – Strategic Development Project Group.
- work with and utilise the RNLD Community of Practice to engage with RNLDs across the region to take forward specific work streams/initiatives being progressed - promoting opportunities to enhance professional leadership capacity and capability within RNLD nursing
- provide leadership and support for and support to all the nursing fields of practice and other professional groups who work with people with learning disabilities in Northern Ireland
- work to support the implementation of regionally agreed initiatives in local areas, facilitating action and communicating progress within their organisation
- when requested, give timely feedback to the group or to those in work streams on proposals, decisions or actions

Individual members of the RNLD ERG group will:
- Take a leadership role for specific elements of the work streams on behalf of the Registered Nurse Learning Disabilities – Strategic Development Project Group
- Actively engage and contribute to the work streams stemming from the RNLD ERG and work to agreed timescales
- Work to support the implementation of regionally agreed initiatives in local areas, facilitating action and communicating progress within their organisation

Membership

The RNLD ERG is comprised of individuals from a range of relevant organisations and sectors and involves representation from people with learning disabilities and family members/carers representation - as part of the process of implementation including:

- Prof Owen Barr, Professor of Nursing and Intellectual Disabilities,
- Ulster University, Chair
- Siobhan Rogan Assistant Director for Mental Health and Learning Disability, PHA.
- Frances Cannon, Associate Senior Professional Officer, NIPEC (Project Support)
- Michelle Curran, RNLD Consultant Nurse, BHSCT
- Michael McBride RNLD, Children's, BHSCT
- Frances Maguire, RNLD Adult, BHSCT
- Barbara Tate, Trainee RNLD Consultant Nurse SEHSCT
- Julie Richie, representing RNLD Children's SEHSCT replaced by Sharon Ogle Dec2023
- Stephanie Price Lead Nurse Adult SEHSCT
- Maureen Roberts Trainee RNLD Consultant Nurse SHSCT
- Donna Grant representing RNLD Children's SHSCT
- Oisin McAuley representing RNLD Adult SHSCT
- Seamus Coyle RNLD Trainee Consultant Nurse NHSCT
- Rhona Brennan Operational Lead NHSCT
- Michelle Angelone representing RNLD Children's NHSCT
- Clionagh McElhinney Trainee RNLD Consultant Nurse WHSCT
- Janet Doherty Head of Service Lead Nurse Adult WHSCT
- Donna Milligan Community Nurse – representing Children's WHSCT
- Denise McGill Triangle Housing replaced Dec 2023 by Marius Coman
- Rosaline Kelly, Senior Nurse Professional Practice, Royal College of Nursing
- Damian McAleer, Nurse Education Consultant, Clinical Education Centre,
- Nicola McCann, Learning Disability Inspector, Regulation and Quality Improvement Authority
- Maurice Devine, Professional Lead (Nursing), Open University
- Dr Lynne Marsh, Senior Lecturer, Queens University Belfast
- Leslie–Anne Newton Arc UK (circulation only)
- Claire Thompson pre-registration Student QUB

Where required the RNLD ERG will identify and co-opt other members to contribute to the group were relevant.

RNLD ERG Meetings
- Meetings of the RNLD ERG will be held monthly
- Meetings will only proceed of there is representation from the five HSC Trusts and other groups in memberships of the ERG
- Meetings will take place using a blended approach including face to face meetings hosted across the region and virtual meetings (Microsoft Teams)
- Where required the RNLD ERG will identify and co-opt other colleagues to contribute to the group were relevant.
- When absence from meetings is unavoidable members will provide a short briefing paper ahead of the planned meetings.

Review and evaluation
There is a requirement for the RNLD ERG to provide a formal report on activity on an annual basis to the Chief Nursing Officer. Review and evaluation of progress, however, will be a continual dynamic by the RNLD ERG membership.

To ensure the TOR remain relevant and reflect current professional and strategic direction they will be reviewed at the first meeting of each year.

Review Date January 2024.

Terms of Reference

Registered Nurse Learning Disabilities Expert Reference Group (RNLD ERG)

Communities of Practice

This paper sets out the Terms of Reference for a Registered Nurse Learning Disabilities Communities of Practice.

BACKGROUND

In 2014 in response to the Strengthening the Commitment[1] - NI Action Plan the NI Collaborative was established to take forward the actions from the NI Action Plan. The NI Collaborative at that time requested NIPEC and the Royal College of Nursing, to establish a regional Professional Development Network/Forum for learning disabilities nurses

In 2019 the CNOs across the UK noted their intention to stand down the four countries Strengthening the Commitment groups. This coincided with the Department of Health (DoH) decision to undertake a review of the role of registered nurses; learning disabilities workforce in Northern Ireland. By agreement with the CNO it was intended that the recommendations from the review would inform the activity of the Collaborative going forward.

The 31st January 2020 marked the start of the pandemic. During the pandemic meetings and activity of the Collaborative and the Regional Professional Development Network/ Forum for learning disabilities nurses was paused at the request of the HSC due to system pressures. Scheduled meetings were impacted significantly with only two catch up-meetings during this time.

The DoH is now concluding the review of the role of the Registered Nurses Learning Disabilities workforce in Northern Ireland (pending publication) and the CNO has commissioned NIPEC to establish a Registered Nurse Learning Disabilities – Strategic Development Project Group to take forward the outworking's of the review.

In September 2022 the CNO and the Chief Executive of NIPEC asked the Collaborative to provide a high-level overview of work of the NI Collaborative with a view to a refresh /rebrand and re-energising of the group whose primary function going forward would be to support the outworking's of the Registered Nurse Learning Disabilities – Strategic Development Project Group.

To that end the NI Collaborative members met on the 8th November 2022 and agreed the re-energised group should be known as the Registered Nurse Learning Disability Expert Reference Group (RNLD ERG). The RNLD ERG has since met on several occasions and have requested that the Regional Professional Development Forum is rebranded as an RNLD Communities of Practice (CoP) open to all Registered Learning Disabilities Nurses. This direction aligns the group with recommendations of the Nursing and Midwifery Task Group.

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1   The Scottish Executive (2012). The Report of the UK Modernising Learning Disabilities Nursing Review: Strengthening the Commitment. Edinburgh; Scottish Government.

To that end the RNLD ERG have requested NIPEC to establish an RNLD CoP open to all Registered Learning Disabilities Nurses and other nurses who have an interest in supporting people with learning disabilities - across all settings to include HSC Trusts, the education sector and the independent/voluntary sector.

Purpose: Terms of Reference

I. To provide a mechanism to share best practice in learning disability nursing, promote continuous professional development and provide a platform to explore registration specific and wider professional issues.

II. To champion professional recognition of the valuable and important role of learning disability nursing

III. To provide networking opportunities which support and promote professional connectedness

IV. To provide a mechanism that facilitates communication with and to the learning disabilities nursing workforce on professional matters

V. To support the development of links with other organisations as appropriate

Facilitation and administrative support will be offered by NIPEC. It is anticipated a minimun of three meetings a year will be scheduled and will be a mix of virtual and face to face. Informtion and dissemination of RNLD CoP meetings will be disseminated via the membership of the RNLD ERG.

Role of the Co-Chairs
- agree agenda for each meeting
- invite guest speakers as appropriate
- guide the meeting in a facilitative manner where discussions need an outcome and ensures an action is agreed
- take brief notes and agreed action points of discussions
- ensure room bookings/virtual arrangments for meetings are made

Conduct and Confidentiality
All members of the CoP are bound by the rules of confidentiality and ensure information is shared appropriately.

Finance and Resources
There are no specific resources available to support this initiative however the contribution of members and their employers are recognised as the main resource through which the CoP will be established and maintained. NIPEC will endeavour to provide modest funding to facilitate meetings which will be rotated around venues.

Accountability
The CoP will provide a verbal or written report of activity to the RNLD ERG.

Review
These Terms of Reference will be reviewed each year. Date for Review April 2024

Appendix 4

HSC TRUST

RNLD Workforce Scoping Tool as at 31 October 2022

Please state your HSC Trust:

Please provide information of the total funded Learning Disabilities Nursing staffing establishment within your Trust as at 31 October 2022.

There are 2 sections in this Scoping Tool.

Section 1: aims to gather data relating to Adult Learning Disabilities Nursing services

Section 2: aims to gather data relating to Children's Learning Disabilities Nursing services

If *you have nursing staff who are employed in your Trust to meet the needs of adults with a Learning Disability that are not RNLDs, but have a registration from another field of practice, (e.g. Adult, Mental Health or Children) please respond in Question 7.*

Section 1: Adult Services

1. Adult: Inpatient Staffing Establishment

Job Title	Band	Funded establishment	Head count	WTE	Comments
Lead Nurse/clinical manager	8c				
Lead Nurse/clinical manager	8b				
Lead Nurse/clinical manager	8a				
Ward Sister/Charge Nurse	7				
Deputy WS/CN	6				
Staff Nurse	5				
Other					
HCSW/Nursing support worker/ Band	3				

Job Title	Band	Funded establishment	Head count	WTE	Comments
HCSW/Nursing support worker/Band	2				
Comments (including information on any joint appointments between more than one employer)					
No recurrent funding has been received by the trust – the above posts are in relation to the new LD 3 Bedded Ward at Holywell					

1a. Adult: Inpatient Agency Cover of shifts August to October 2022

Agency Cover for Adult: Inpatient	Band	Aug 2022 Hrs filled	Sept 2022 Hrs filled	Oct 2022 Hrs filled
Ward Sister/Charge Nurse	7			
Deputy WS/CN	6			
Staff Nurse	5			
HCSW/Nursing support worker	3			
HCSW/Nursing support worker	2			

1b. Adult: Inpatient Agency Cover of shifts by RNLD or Other RN August to October 2022

Agency Cover for Adult: Inpatient Hrs Filled by RNLD or Other RN	Band	Aug 2022 Hrs filled by		Sept 2022 Hrs filled by		Oct 2022 Hrs filled by	
		RNLD	Other RN	RNLD	Other RN	RNLD	Other RN
Ward Sister/Charge Nurse	7						
Deputy WS/CN	6						
Staff Nurse	5						
Other							

1c. Line Management Arrangements

Please describe line management arrangements for RNLDs working in the inpatient setting.

1d. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs within the inpatient setting.

1e. Service Development

Please detail proposed developments within Learning Disabilities services

- current developments
- proposed developments
- longer term developments

1f. Workforce Needs

Please detail workforce needs to meet developments within Learning Disabilities services.

2. Adult: Community Nurse part of Statutory Trust Team for example integrated care team for Adult Learning Disabilities Services

Job Title	Band	Funded establishment	Head Count	WTE	Additional SPQ Community Learning Disabilities Qualification yes/no
Lead Nurse/clinical manager - *please specify*	8c				
Lead Nurse/clinical manager - *please specify*	8b				
Lead Nurse/clinical manager - *please specify*	8a				
Community Learning Disabilities Team Leader	7				
Community Learning Disabilities Sister/Charge Nurse	6				
Community Learning Disabilities Nurse Staff Nurse	5				
Community Learning Disabilities HCSW/Nursing support worker/Band	3				
Community Learning Disabilities HCSW/Nursing support worker/Band	2				
Comments (including information on any joint appointments between more than one employer)					

2a. Adult: Community Agency Cover of shifts August to October 2022

Agency Cover for Adult: Community: Services	Band	Aug 2022 Hrs filled by	Sept 2022 Hrs filled by	Oct 2022 Hrs filled by
Ward Sister/Charge Nurse	7			
Deputy WS/CN	6			
Staff Nurse	5			
Other				

2b. Adult: Community Agency Cover of shifts by RNLD or Other RN August to October 2022

Agency Cover for Adult: Community: Hrs Filled by RNLD or Other RN	Band	Aug 2022 Hrs filled by		Sept 2022 Hrs filled by		Oct 2022 Hrs filled by	
		RNLD	Other RN	RNLD	Other RN	RNLD	Other RN
Ward Sister/Charge Nurse	7						
Deputy WS/CN	6						
Staff Nurse	5						

2c. Line Management Arrangements

Please describe line management arrangements for RNLDs working as a Community Nurse as part of Statutory Trust Team.

2d. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working as a Community Nurse as part of Statutory Trust Team.

2e. Service Development

Please detail proposed developments within Community Learning Disabilities services:

- current developments
- proposed developments
- longer term developments

2f. Workforce Needs

Please detail workforce needs to meet developments within Community Learning Disabilities services.

3. Adult: Respite/Residential Settings

Job Title Please specify below	Band	Funded establishment	Head Count	WTE	Comments
Nurse	5				
HCSW/Nursing support worker/Band	3				
HCSW/Nursing support worker/Band	2				

3a. Line Management Arrangements

Please describe line management arrangements for RNLDs working in Adult Respite/Residential settings.

3b. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in Adult Respite/Residential settings.

3c. Service Development

Please detail proposed developments within Learning Disabilities services in Adult Respite/Residential settings:

- current developments
- proposed developments
- longer term developments
- Funding in place to increase bed capacity in step down respite bed in Holybank

3d. Workforce Needs

Please detail workforce needs to meet developments in Adult Respite/Residential settings.

4. Adult: Supported Living Settings

Job Title Please specify below	Band	Funded establishment	Head Count	WTE	Comments
Nurse	6				
HCSW/Nursing support worker/Band excluding Social care assistants	3				
HCSW/Nursing support worker/Band excluding Social care assistants	2				
Additional Comments:					

4a. Line Management Arrangements

Please describe line management arrangements for RNLDs working in Adult Supported Living settings.

4b. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in Adult Supported Living settings.

4c. Service Development

Please detail proposed developments within Learning Disabilities services within Adult Supported Living settings:

- current developments
- proposed developments
- longer term developments

4d. Workforce Needs

Please detail workforce needs to meet developments in Adult Supported Living settings.

5. Adult: Day Care/Day Opportunities setting

Job Title Please specify below	Band	Funded establishment	Head Count	WTE	Comments
Nurse	7				
Nurse	5				
HCSW/Nursing support worker/Band excluding Social care assistants	3				
HCSW/Nursing support worker/Band excluding Social care assistants	2				
Additional Comments: Band 7 Nurse is the manager of an adult centre, can be either Nursing/Social Work background					

5a. Line Management Arrangements

Please describe line management arrangements for RNLDs working in a Day Care/Day Opportunities setting.

5b. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in a Day Care/Day Opportunities setting.

5c. Service Development

Please detail proposed developments within Learning Disabilities services within Day Care/Day Opportunities settings:

• current developments
• proposed developments
• longer term developments

5d. Workforce Needs

Please detail workforce needs to meet developments in Day Care/Day Opportunities settings.

6. Adult: Total number of RNLDs within the identified age ranges

Age Ranges								
<25	**26-29**	**30-34**	**35-39**	**40-44**	**45-49**	**50-54**	**55-59**	**60+**

7. Total number of nursing staff who are employed in your Learning Disabilities nursing service with a nursing registration/qualification from another field of practice to meet the needs of Adults with a Learning Disability.

Field of Practice	Number	Title Please specify & include all posts between Band 5 - Band 8C
Registered Nurse - Mental Health		
Registered Nurse - Adult		
Registered Nurse - Children's		

8. Designated Learning Disabilities Nursing Roles

Please provide information regarding Designated Learning Disabilities Nursing Roles within your Adult Learning Disabilities Services

Role	Band	Funded establishment	Head Count	WTE	Comments
Behaviour Nurse					
Health Facilitator	6				
Epilepsy Nurse	7				
Forensic Nurse					
Complex Needs Nurse	5				
Other					
Additional Comments					

9. Practice Development and or Education Roles

Do any of the RNLDs have dedicated time to contribute to education for staff or family carers? Please provide details here.

10. Nurse Prescribing

How many RNLDs are on your organisation's Prescribing Register?	Number of Prescribers
V100	
V150	
V300	
Additional Comments There are 3 nurses who have V300 but are not on the organisations register and not actively using the qualification	

11. Other funded nursing roles in services for people with a Learning Disability not already captured above.

If there are any areas not captured in the questionnaire above can you please provide relevant information in the box below:

Comments

Section 1	
Date of completion	
Completed by	
Signature	

Section 2: Learning Disabilities Nurses working in Inpatient Children's Services

If you have nursing staff who are employed in your Trust to meet the needs of children with a Learning Disability that are not RNLDs, but have a registration from another field of practice (e.g. Adult, Mental Health or Children) please respond in question 6.

Children's Services

1 Children's: Inpatient Funded staffing establishment

Job Title Please specify below	Band	Funded establishment	Head Count	WTE	Comments
Lead Nurse/clinical manager	**8c**				
Lead Nurse/clinical manager	**8b**				
Lead Nurse/clinical manager	**8a**				
Ward Sister/Charge Nurse	**7**				
Deputy WS/CN	**6**				
Staff Nurse	**5**				
HCSW/Nursing support worker	**3**				
HCSW/Nursing support worker	**2**				
Comments (including information on any joint appointments between more than one employer)					

1a. Children's: Inpatient Agency Cover of shifts August to October 2022

Agency Cover for Inpatient Children's	Band	Aug 2022 Hrs filled	Sept 2022 Hrs filled	Oct 2022 Hrs filled
Ward Sister/Charge Nurse	**7**			
Deputy WS/CN	**6**			
Staff Nurse	**5**			
HCSW/Nursing support worker	**3**			
HCSW/Nursing support worker	**2**			

1b. Children's: Inpatient Agency Cover of shifts by RNLD or other RN August to October 2022

Agency Cover for Inpatient Children's Hrs Filled by RNLD or Other RN	Band	Aug 2022 Hrs filled by		Sept 2022 Hrs filled by		Oct 2022 Hrs filled by	
		RNLD	Other RN	RNLD	Other RN	RNLD	Other RN
Ward Sister/Charge Nurse	7						
Deputy WS/CN	6						
Staff Nurse	5						

1c. Line Management Arrangements

Please describe line management arrangements for RNLDs working in inpatient Children's Services

1d. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in inpatient Children's Services

1e. Service Development

Please detail proposed developments within inpatient Children's Learning Disabilities services:

- current developments
- proposed developments
- longer term developments

1f. Workforce Needs

Please detail workforce needs to meet developments within Learning Disabilities services.

2. Children's: Community Nurse as part of Statutory Trust Team, for example, integrated care team for Learning Disabilities services

Job Title	Band	Funded Establishment	Head Count	WTE	Additional SPQ Community Learning Disabilities Qualification yes/no
Lead Nurse/clinical manager - *please specify*	8c				
Lead Nurse/clinical manager - *please specify*	8b				
Lead Nurse/clinical manager - *please specify*	8a				
Community Learning Disabilities Team Leader	7				
Community Learning Disabilities Sister/Charge Nurse	6				
Community Learning Disabilities Nurse Staff Nurse	5				
Community Learning Disabilities HCSW/Nursing support worker/Band	3				
Community Learning Disabilities HCSW/Nursing support worker/Band	2				
Comments (including information on any joint appointments between more than one employer)					

2a. Children's: Community Agency Cover of shifts August to October 2022

Agency Cover for Community: Children's:	Band	Aug 2022 Hrs filled by	Sept 2022 Hrs filled by	Oct 2022 Hrs filled by
Ward Sister/Charge Nurse	7			
Deputy WS/CN	6			
Staff Nurse	5			
HCSW/Nursing support worker	3			
HCSW/Nursing support worker	2			

2b. Children's: Community Agency Cover of shifts by RNLD or Other RN August to October 2022

Agency Cover for Community: Children's Hrs Filled by RNLD or Other RN	Band	Aug 2022 Hrs filled by		Sept 2022 Hrs filled by		Oct 2022 Hrs filled by	
		RNLD	Other RN	RNLD	Other RN	RNLD	Other RN
Ward Sister/Charge Nurse	7						
Deputy WS/CN	6						
Staff Nurse	5						

2c. Line Management Arrangements

Please describe line management arrangements for RNLDs working in Children's Community Nurse services as part of Statutory Trust Team

2d. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in Children's Community Nurse services as part of Statutory Trust Team

2e. Service Development

Please detail proposed developments within Children's Community Nurse services:

- current developments
- proposed developments
- longer term developments

2f. Workforce Needs

Please detail workforce needs to meet developments within Learning Disabilities services.

Workforce needs only funded for 2 LD nurses – workforce plans will increase as the services development

3. Children's: Respite/Residential Living Settings

Job Title Please specify below	Band	Funded establishment	Head Count	WTE	Comments
Learning Disability Nurse	**5**	1	1	1	
Additional Comments					

3a. Line Management Arrangements

Please describe line management arrangements for RNLDs working in Children's Respite/Residential Living settings.

3b. Professional Supervision Arrangements

Please outline professional supervision arrangements of RNLDs working in Children's Respite/Residential living settings.

3c. Service Development

Please detail proposed developments within Children's Respite/Residential living settings:

- current developments
- proposed developments
- longer term developments

NONE

3d. Workforce Needs

Please detail workforce needs to meet developments within Learning Disabilities services.

4. Children's: Special School

Job Title	Band	Funded establishment	Head Count	WTE	Comments
Please specify					
Additional Comments No Learning Disability Nurses employed in Special Schools					

4a. Line Management Arrangements

Please describe line management arrangements for RNLDs working in Children's Special Schools

4b. Professional Supervision Arrangements

Please outline line professional supervision arrangements for RNLDs working in Children's Special Schools.

4c. Service Development

Please detail proposed developments within Learning Disabilities Children's Special Schools services:
- current developments
- proposed developments
- longer term developments

4d. Workforce Needs

Please detail workforce needs to meet developments within Learning Disabilities services.

5. Total number of RNLDs working in Children's Learning Disabilities Services within the identified age ranges

Age Ranges								
<25	26-29	30-34	35-39	40-44	45-49	50-54	55-59	60+

6. Total number of nursing staff who are employed in your Children's Learning Disabilities Nursing service with a nursing registration/qualification from another field of practice to meet the needs of Children with Learning Disabilities.

Field of Practice	Number	Title Please specify & include all posts between Band 5 - Band 8C
Registered Nurse - Mental Health		
Registered Nurse - Adult		
Registered Nurse - Children's		

7. Designated Learning Disabilities Nursing Roles

Detail the number of RNLD roles within your services for children with a Learning Disability who work in designated roles

Role	Band	Funded establishment	Head Count	Service area/Setting
Behaviour Nurse				
Health Facilitator				
Epilepsy Nurse				
Other				
Additional Comments All band 7 Learning Disability nurses working as behaviour nurse				

8. Practice Development and or Training Role

Do any of the RNLDs in Children's Learning Disabilities services have dedicated time to contribute to education for staff or family carers? Please provide details here.

9. Nurse Prescribing

How many RNLDs in Children's Learning Disabilities services are on your organisation's Prescribing Register?	Number of Prescribers
V100	
V150	
V300	
Additional Comments None	

10. Other funded nursing roles in Children's Learning Disabilities services not already captured above.

If there are any areas not captured in the above questionnaire can you please provide relevant information in the box below:

Comments None

Section 2	
Date of completion	
Completed by	
Signature	

Appendix 5

Governance and Accountability Structures of RNLDs within the HSC Online Survey

RNLD professional accountability and assurance baseline information

Overview
The Chief Nursing Officer commissioned NIPEC to establish a Task and Finish Group to rapidly build on previous learning. The group will define the roles that RNLDs should be delivering, in line with evidence-based practice, to meet the needs of the population in Northern Ireland. Over the past few decades, in response to a better understanding of how best to meet the needs of the population of people with a learning disability there has been a shift in the strategic direction and associated models of service provision. Meeting the health and social care needs of people with a learning disability in this new landscape has presented both challenges and opportunities for RNLD's. As part of this work we will be examining the most effective structures and processes to enable robust professional governance, accountability and assurance.

Why your views matter
By completing the following questions, you will be informing a baseline in respect of the professional accountability and assurance structures and processes and will informing future planning. Thank you for your support

Questions:
1. Please record your name and title

2. Is there a Lead Nurse professionally accountable for the governance of Registered Learning Disabilities Nursing including: professional workforce planning, standards of care and practice?

3. Is the Lead Nurse for Registered Nursing Learning Disabilities a trained and registered Learning Disability Nurse?

4. What is the current Banding of the Lead Nurse in your Trust:

5. Is the Lead Nurse accountability for RNLD Trust wide or Service Area/Directorate specific?

6. If not Trust wide and covers one or a range of Service Areas/Directorates, please specify

7. Is the professional accountability responsibilities outlined in the Lead Nurse Job description?

8. In which Directorate/Division is the Lead Nurse employed?

9. Which profession does the Lead Nurse operationally report to?

10. Does the Lead Nurse manage staff employed specifically to support their professional accountability role?

11. Does the Lead Nurse sit as a functioning member of the Trust professional fora as part of the professional governance processes?

12. As part of the professional governance reporting processes are there specific reports for Registered Learning Disabilities Nursing?

13. Are you confident that the current processes and structure provide robust professional accountability and governance for RNLD workforce planning, practice and standards of care?

14. Please provide any further information in respect of the questions in the survey and to inform a RNLD professional accountability and assurance framework:
    For further information please contact enquiries@nipec.hscni.net;

Appendix 6

Designated Roles and Banding Across the HSC Trusts Adult and Children's Services: (Data taken from the Scoping exercise undertaken by the RNLD Strategic Workforce Development Group)

Designated Role	Trust A	Trust B	Trust C	Trust D	Trust E
Behaviour Nurse	1X Band 7 1x Band 6	No	No	No	2 x Band 7
Forensic Nurse	0	1x Band 6	No	No	1 x Band 7
Health Facilitator	2 2x Band 7	3 x Band 6	3x Band 6 HC 2	No	1 Band 7
Epilepsy Nurse	1* Band 7	2 X Band 7 1 x Band 6 HC 5	2 Band 7	1x Band 7	1 Band 7
Practice Educator Facilitator	No	1 Band 7	NO	NO	NO
Community Access Officer	NO	NO		NO	NO
Nurse Development Lead	NO	1x Band 7	NO	NO	NO
Acute Liaison	1 Band 7	No	2 x Band 7 Practice Educator Nurse with Acute Liaison Role	2 x Band 7	No
Mental Health Liaison	No	No	No	1x Band 7	NO
Transition Nurse	No	1X Band 7 1x Band 6 HC 2.8	No	No	NO
Complex Health Needs	1* Band 7	7 3 x Band 6 4x Band 5	2 2 x Band 5 2 x Band 5 nurses employed to support service user in own home	No	No
Trainee RNLD Consultant Nurse	RNLD Consultant Nurse	yes	yes	yes	yes
Monitoring Officer	No	1 Band 7	No	No	NO

Designated Learning Disabilities Nursing Roles within services for Adults with a Learning Disability

*dedicated time to contribute to education for staff and family carers

Designated Learning Disabilities Nursing Roles within services for Children with a Learning Disability

Designated Role	Trust A	Trust B	Trust C	Trust D	Trust E
Behaviour Nurse	1X Band 7	No	5 x Band 7	No	No
Health Facilitator	No	No	No	No	No
Epilepsy Nurse	No	No	No	No	No
ID CAMHS		1 x Band 8a 1x Band 7 1x Band 6		NO	

Appendix 7

Date	Engagement Activities	Numbers and participants
28 April 2023	**RNLD Communities of Practice** **Virtual Meeting 1:** RNLD Strategic Workforce Development Project overview	86 participants (RNLDs, RNs, Medical staff)
24 Oct 2023	**Virtual Meeting 2:** The Model for RNLD Nursing and the recommendations from the RNLD Strategic Workforce Development Project	94 participants RNLDs RNs, medical staff)
27th February 2024	**Virtual Meeting 3:** Update on the Model for RNLD Nursing and the recommendations from the RNLD Strategic Workforce Development Project	81 participants attended (RNLDs and RNs)
	People with a Learning Disability and their Carers	Link to Flyer attached advertising information Event on the 19th September 2023
19 September 2023	**NIPEC Virtual Event: People with a Learning Disability and their Carers** Topic Strategic Workforce Development Project overview: • A report on the future model of nursing for Registered Nurses for people with learning disabilities • What the project aims to achieve and work so far	21 people attended including FINI members
2nd October	Correspondence from Families Involved Northern Ireland (FINI)	
3rd November	Response email from Strategic Workforce Development Project Group to FINI members	

Date	Engagement Activities	Numbers and participants
30th June 2023	Patient & Client Council (PCC) Service Users and their Carers Events	0 people attended
18th July 2023	Patient & Client Council (PCC) Service Users and their Carers Events	people attended
19th December 2023	Patient & Client Council (PCC) Service Users and their Carers Events	5 people attended
16th January 2024	Patient & Client Council (PCC) Service Users and their Carers Events	5 people attended
19th September 2023	Used at the engagement with service users and carers event 19/09/2023 was shared with the RNLD Consultant Nurses for dissemination locally and at local RNLD Professional Team Meetings	To date 145 RNLDs across a range of bands attended sessions delivered locally by the RNLD Consultant Nurses. Power Point presentation on the Equity of Access Report and the RNLD Model
3rd October 2023	Masterclass (3/10/23) for RNLD Consultant Nurses to support local delivery of the presentation on the Equity of Access and Outcome Report and RNLD Model	Participants included RNLDs, CNLDs Managers in Community settings. **RNLD Consultant Nurses engage with the RNLD workforce on an ongoing basis.**
Initial phone call 24/10/23	**Highlighter Newsletter** Plans to include a piece in the Highlighter Newsletter - a newsletter which is designed specifically for people with a learning disability	
	Mae Murray Foundation Dates offered to the Mae Murray Foundation	

Engagement - Feedback from those close to people with a learning disability and staff

Feedback and comments from those close to people with a learning disability

- Recognition of the role of the RNLDs in increasing health outcomes for people with a learning disability over the life time of a person with a learning disability.

- Examples of the significant variation in service provision across the region

- Carers highlighted the need for more equitable services - both hospital and community - that are accessible to all

- Carers gave very poignant examples of the difficulties they encountered in accessing services for their loved one, but also countered this by giving example of the difference RNLD can make in ensuring reasonable adjustments are put in place so people a learning disability can access services in a timely way

- Recognition that RNLDs can make a huge impact in advocating for reasonable adjustments and supporting implementation - carers stressed how important this is when the person no longer has family

Register Nurse Learning Disability (RNLDs)

Feedback from RNLDs included:

- Frustration that their role is often undervalued and the implementation of this model was an opportunity to get RNLDs back to what hey had trained to do

- Exciting times ahead as currently there is lack of strategic direction standardisation and regional agreement for the role of RNLDs

- Lack of a career pathway for RNLDs, culminating in variation of RNLD roles with similar responsibilities

- Not all posts requiring the skills and expertise of an LD Nurse reflect this in the job title, therefore, the contribution of the Nurse may not be clear

- Lack of career progression with less opportunities and limited career pathways for LD Nurses who aspire to middle and senior professional posts related to their specific field of practice

- A number of senior positions do not require the post holder to hold registration with the NMC. It is suggested; this has and will continue to have an impact on the visible nurse leadership contribution by RNLDs Nurses at a senior level

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