

Why you should read this article:

- To acknowledge the significant health inequalities experienced by people with learning disabilities and how these affect their life expectancy and quality of life
- To learn about the RCN Foundation's Inclusive Health programme, which aims to support learning disability nurses in addressing these inequalities through research and education
- To recognise how co-production with people with lived experience of learning disabilities is central to shaping research and education initiatives

Developing a research and education programme to enhance the lives of people with learning disabilities

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Abstract

People with learning disabilities experience significant health inequalities, leading to reduced life expectancy and poorer health-related quality of life outcomes. The RCN Foundation, an independent charity supporting nursing and midwifery, has launched the Inclusive Health programme to address these disparities. This initiative supports learning disability nursing through research, education and advanced practice scholarships. The programme includes nine research projects, focusing on workforce challenges, access to healthcare, the effect of annual health checks and the role of learning disability nurses in social care. Co-production is central, ensuring people with lived experience of learning disabilities contribute to shaping initiatives. This article explores the literature on health inequalities, the declining learning disability nursing workforce and the importance of evidence-based, person-centred care. It also outlines the RCN Foundation's commitment to reducing health disparities through research, innovation and education, ultimately aiming to improve health-related quality of life outcomes for people with learning disabilities across the UK.

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Keywords

diversity, equality, inclusion, learning disability, management, patient outcomes, patients, professional, quality of life, service improvement, workforce, workforce planning

A LEARNING disability is a lifelong condition that significantly affects a person's ability to undertake activities of daily living, understand new or complex information and learn new skills (Mencap 2025a, Office for Health Improvement and Disparities 2025). Approximately 2.16% of adults in the UK have a learning disability, equivalent to 1.2 million

people (Office for National Statistics 2024, Mencap 2025b).

As a result of improved health surveillance initiatives, there is compelling evidence that people with lived experience of learning disabilities have significant health challenges combined with greater health inequalities, compared with the wider population. Such initiatives include

the Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR) programme in England (King’s College London 2023), the Welsh Government overview of mortality among people with learning disabilities in Wales (Watkins and Jones 2024) and Cooper et al’s (2022) investigation of the health, mortality and healthcare inequalities experienced by people with learning disabilities and autistic people and their determinants in Scotland.

Health inequalities are unjust and avoidable differences in health outcomes across the population and between different societal groups (World Health Organization 2018). These inequalities are exacerbated by the deprivation gap, which is the difference in life expectancy between people who live in the most deprived and least deprived areas of the country (King’s Fund 2024). For people with lived experience of learning disabilities, such factors combine to result in premature deaths and greatly reduced health-related quality of life outcomes (Robertson et al 2018, National Institute for Health and Care Excellence 2021, Cooper et al 2022, King’s College London 2023, Rainer and Abdinasir 2023, Watkins and Jones 2024, Alzheimer’s Society 2025).

The RCN Foundation is an independent charity whose purpose is to support and strengthen nursing and midwifery to improve the health and well-being of the public. In view of the compelling evidence on health inequalities for people with learning disabilities, the RCN Foundation identified learning disability nursing as a priority area of work. In late 2023, the RCN Foundation launched Inclusive Health – Enhancing the Lives of Individuals with Learning Disabilities, a research and education programme aimed at addressing health inequalities and premature deaths for people with lived experience of learning disabilities by enhancing health-related quality of life outcomes through evidence-based, person-centred nursing care.

The programme also aligns with the strong equality, diversity and inclusion ethos that the RCN Foundation applies to all its work, with the NHS Race and Health Observatory (2023) identifying that the average life expectancy for people with learning disabilities from the global majority (those from black, Asian, mixed and other ethnic groups) was 34 years, compared with 62 years for people denoted as white.

This article explores the health inequalities experienced by people with learning disabilities, the declining learning disability nursing workforce in the UK and the importance of evidence-based, person-centred care. It also outlines the RCN Foundation’s commitment to reducing health disparities through research, innovation and education, ultimately aiming to improve health-related quality of life outcomes for people with learning disabilities across the UK.

Learning disability nursing workforce in the UK

When designing the Inclusive Health programme, the RCN Foundation explored the contemporary landscape of learning disability nursing across the UK.

The registered nurse for learning disability (RNLD) workforce is a group of highly educated professionals who demonstrate the knowledge, skills, attitudes, understanding and competence required to deliver expert, evidence-based, person-centred care to people with lived experience of learning disabilities across the lifespan. These transferable skills extend to supporting and educating friends, families and other healthcare professionals across a range of health and social care settings, with the aim of enabling each individual to lead a healthy and fulfilling life (NHS 2025).

Since 2009, the RNLD workforce in England has decreased by 44% (Royal College of Nursing (RCN) 2024). Between 1 April and 30 September 2024, there were 16,837 learning disability nurses on the Nursing and Midwifery Council (NMC)

Key points

- People with learning disabilities experience significant health inequalities, leading to reduced life expectancy and poorer health-related quality of life outcomes
- There is a declining number of registered learning disability nurses in the UK, which adversely affects care provision and service development
- The RCN Foundation has launched a research and education programme to support learning disability nurses in reducing health inequalities and improving health-related quality of life outcomes
- The programme includes nine research projects and an advanced practice scholarship to strengthen the evidence base for learning disability nursing
- People with lived experience of learning disabilities have been actively involved in shaping research and education initiatives

register, compared with 623,224 adult nurses, 101,626 mental health nurses and 60,445 children's nurses (NMC 2024).

To address this issue, the NHS in each country of the UK has a workforce plan that includes strategies to support learning disability nursing. However, workforce challenges remain. Taking England as an example, the NHS Long Term Workforce Plan (NHS England 2023) is based on three priority areas: train, retain and reform. It sets out an ambition to increase learning disability nursing student places by 46% by 2028-2029. However, in 2023 a total of 405 applicants to learning disability nursing courses in England were accepted, representing a 26% decrease from 2022 and a 36% decrease from 2015 (RCN 2024). As a result, many courses have become unviable, and many education providers are withdrawing their undergraduate learning disability nursing provision (Dean 2023).

The demographics of the learning disability nursing student group may provide an explanation for the shortage. Brailsford et al (2024) found learning disability nursing students are often more mature in age and have personal connections to learning disabilities. For many it is a second career, or one they have chosen because they have a relative with a learning disability. With a tendency for mature students to be more debt averse, student recruitment to this field can be affected (Council of Deans of Health 2017).

Practice placement provision is another challenge in learning disability nurse education (Doody et al 2020). The lack of placements in rural settings means that students must relocate to urban areas where placements are more readily available. This is a particular issue in Scotland, and a project in the Inclusive Health programme will identify new practice placement models across Scottish remote and rural settings. The outcomes of this project will be transferable to other UK areas that experience similar challenges.

The lack of a comprehensive dataset related to the UK RNLD workforce across

social care is another issue. Approximately 5,000 RNLDs are practising in social care settings in England; however, it is unclear where they work and what their roles are (RCN 2021). There is an apparent phenomenon of RNLDs working in social care who are deregistering from the NMC, thereby reducing the RNLD workforce across social care. Fewer RNLDs working in these settings means there are fewer supervisors and assessors to meet the NMC's (2023) Standards for Student Supervision and Assessment requirements for practice placement settings. The availability of appropriate and suitable practice placements with RNLD practice assessors and supervisors is fundamental to future undergraduate learning disability nurse education (Doody et al 2020, NMC 2023).

Skills for Care (2024) has published a workforce strategy for adult social care in England that mirrors the areas of focus in the NHS Long Term Workforce Plan (NHS England 2023): attract and retain, train and transform. This strategy recognises that people with learning disabilities often require social care at some time in their lives; however, it presents a more generic workforce approach, with no specific detail on the challenges experienced by social care RNLDs.

To better understand the rates, reasons and effects of RNLDs in social care deregistering from the NMC, a project in the Inclusive Health programme is exploring this phenomenon.

Developing the RCN Foundation's work in learning disability nursing

Stages in the process to develop the Inclusive Health programme are outlined in Box 1.

Once the RCN Foundation had identified learning disability nursing as a priority, the first step in developing the Inclusive Health programme was to hold an in-person collaborative forum in 2019 with key stakeholders from across the UK, ostensibly professionals working in NHS and social care settings and many national learning

disabilities and nursing charities. The 2019 forum was held to:

- » Generate discussion, debate and ideas through which the RCN Foundation could identify specific priorities for how nursing can make a difference to the care of people with learning disabilities.
- » Identify the specific issues and themes that would underpin the work and how best to take these forward.
- » Set out next steps.

The forum adopted a world-café style (a large group discussion, which splits into subgroups who rotate around tables in the room discussing specific points at each table) in which the groups discussed:

- » What exemplary nurse-led care for people with learning disabilities looks like.
- » What are patients' and nurses' experiences of effective and suboptimal care for people with learning disabilities?
- » How can care for people with lived experience of learning disabilities be improved?
- » What improvements are already underway and where are the gaps?
- » What are the responsibilities of all healthcare professionals?
- » How can RNLDs use technology to improve patient care?

From this, the following needs were identified:

- » The need to map service provision to the RNLD role.
- » The need to improve the perception and definition of the RNLD role.
- » The need to undertake a cost-benefit analysis of the contribution of RNLDs to demonstrate the value of the care they provide.

A challenge of the forum was to ensure that the voices of people with lived experience of learning disabilities were heard. It was hoped that one of the charities attending would provide a service user perspective; however, this was not possible, meaning that this aspect was not captured fully at the event. Capturing the voices of people with lived experience of learning disabilities has been addressed through

subsequent scoping activities, where the RCN Foundation's growing experience and understanding of a co-production approach now ensure that the voices of people with lived experience of learning disabilities are central to its work.

After the forum, the RCN Foundation funded research that began with a mixed-methods scoping review of literature to summarise evidence on the contribution of learning disability nurses to improve the health and well-being of people with learning disabilities, now and for the future. The review identified 54 publications detailing 154 learning disability nursing interventions. These were categorised into three themes: implementing nursing procedures; enhancing the effect of services; and enhancing quality of life. The review recommended that a searchable online compendium of learning disability nursing interventions be established and regularly updated (Mafuba et al 2023a).

Box 1. Stages in the process to develop the Inclusive Health programme

- » Stage 1 – initial identification of recruitment and retention challenges experienced by the registered nurse for learning disability (RNLD) workforce, together with the health inequalities, reduced quality of life outcomes and premature death rates for people with lived experience of learning disabilities
- » Stage 2 – inviting a wide range of stakeholders to a collaborative forum on learning disability nursing to explore priorities and gaps in understanding
- » Stage 3 – University of West London scoping review to understand the contribution of nurses to improve the health and well-being of children, adults and older people with learning disabilities now and for the future
- » Stage 4 – further scoping by the RCN Foundation's head of grants and impact (the first author of this article) involving people with lived experience, healthcare professionals, educators, policymakers and academics at a variety of levels of nursing to understand further the challenges experienced by the RNLD workforce and how this affects health inequalities and health-related quality of life outcomes for individuals with lived experience, including country-specific issues
- » Stage 5 – synthesising the data from the stakeholder engagement, the evidence base and the University of West London scoping review relating to health-related quality of life outcomes and health inequalities for people with lived experience to identify gaps in the evidence base which could be addressed through primary research and an education programme
- » Stage 6 – RCN Foundation board of trustees' approval for the Inclusive Health – Enhancing the Lives of Individuals with Learning Disabilities programme
- » Stage 7 – delivery of the programme
- » Stage 8 – impact assessment of each component of the programme through the RCN Foundation's bespoke impact assessment framework
- » Stage 9 – formal evaluation of the effect of the overall programme will adopt a longitudinal approach

Next, an online survey of 230 learning disability nurses from seven countries identified 878 interventions, categorised into five themes: implementing nursing procedures; enhancing the effect of learning disability services; enhancing the effect of mainstream services; enhancing quality of life; and enhancing learning disability nursing practice (Mafuba et al 2023b). The findings from the quantitative questions in the online survey indicated that most respondents considered a compendium of learning disability nursing interventions a useful resource (Mafuba et al 2023c). Case study examples were gathered from the online survey and showed that learning disability nurses were often working at an advanced practitioner level (Mafuba et al 2023d).

Mafuba et al's (2023a) scoping review provided an informative baseline of the range of nursing interventions RNLDs implement when caring for people with learning disabilities. However, the scoping review, compendium and case studies did not identify the effect of these in the context of health inequality and health-related quality of life outcomes. A limitation of the scoping review was that it focused on the contribution of

Box 2. Comments from individuals with lived experience of learning disabilities

- » 'Nurses need to be paid more so that there are more of them to look after us'
- » 'People need to learn from those with a learning disability... particularly when they are being trained and those working in a general setting'
- » 'It's hard to access learning disability (and mental health) services in remote and rural settings'
- » 'Nurses fail to use the right resources to communicate with those with a learning disability - increase the use of digital technology to explain things before going into hospital'
- » 'When there is a learning disability nurse in the surgery, they explain the care to the individual better'
- » 'Access to annual health checks is a postcode lottery in some countries'
- » 'Community learning disability teams are brilliant. They bring everyone together to work together: nurses; psychology groups; speech and language therapy'
- » 'There is the need for more support workers'

nursing to the health of people with learning disabilities, meaning that the voice of individuals with lived experience was unrepresented.

In view of this, and the significant health inequalities identified through other data, the focus of the programme moved to health inequality. The RCN Foundation undertook further wide-reaching scoping work on the post-coronavirus disease 2019 (COVID-19) landscape of contemporary UK learning disability nursing. This included hearing from people with lived experience of learning disabilities and their carers, RNLDs, policymakers, educators and academics from across the UK. This scoping work identified significant gaps, concerns and challenges across learning disability nursing practice, education, research, leadership and management about the significant health inequality that individuals with lived experience of learning disabilities continue to experience.

Box 3. Aim and objectives of the Inclusive Health programme

Aim

The aim of the RCN Foundation's learning disability programme of grant-making is to enable registered nurses for learning disability (RNLDs) to reduce health inequality and enhance health-related quality of life outcomes for people with lived experience of learning disabilities

Objectives

- » To enhance the knowledge, skill and competence of nurses and midwives caring for people with learning disabilities through education
- » A programme of education grants to support nurses, midwives, nursing associates and healthcare and maternity support workers to develop their knowledge, understanding and competence, to practise evidence-based, person-centred care for those with lived experience of learning disabilities and any comorbidities they may experience
- » To build the evidence base which underpins learning disability nursing
- » To reduce health inequality and premature deaths for those with lived experience of learning disabilities across a range of healthcare settings in the UK, through a programme of research led by people with lived experience of learning disabilities and RNLDs. This programme of research will contribute to the evidence base which underpins learning disability nursing practice by identifying and addressing the gaps in the evidence base

Mafuba et al's (2023a, 2023b, 2023c, 2023d) findings, combined with the outcomes of the RCN Foundation's scoping work, were synthesised into the Inclusive Health programme.

Contribution of people with lived experience of learning disabilities

The contribution of people with lived experience of learning disabilities has been central to co-producing the

Inclusive Health programme. The RCN Foundation's scoping work involved capturing the lived experience of individuals with learning disabilities through online and in-person discussions between the RCN Foundation's head of grants and impact (the first author of this article), individuals and their carers or supporters. The discussions were driven by the individuals, who were given time and space to discuss and explain their

Table 1. Research projects in the Inclusive Health programme and the rationale for their inclusion

Project	Rationale for inclusion
1. The economic case for investing in the registered nurse for learning disability (RNLD) field and the effect this has on health-related quality of life outcomes across the UK	Identified from the collaborative forum in 2019
2. A study to evaluate the effects of RNLDs' contribution to reducing health inequality and premature death for people with lived experience of learning disabilities	Identified as a need from academics to synthesise the current contribution of RNLDs to addressing health inequality, therefore providing a baseline for current practice and to identify gaps in the evidence base
3. The development of a co-designed tool to assist people with lived experience of learning disabilities to access urgent and emergency care in times of ill health	Identified as a need by RNLDs working in UK urgent and emergency care and individuals with lived experience of learning disabilities
4. A project based in Scotland which develops equitable access to practice learning experiences for undergraduate learning disability nursing students, including developing new and non-traditional placement settings that reflect emerging roles of learning disability nursing	Challenges with student recruitment in remote and rural settings due to practice placement availability were identified through reports and discussion with the Scottish Government
5. A study to analyse and evaluate the effect of annual health checks on reducing health inequalities and premature death for those with a learning disability. The output will be a national, evidence-based model for annual health checks which makes best use of digital technologies for the assessment and recordkeeping and communication of need. Recommendations will also be made for the education, training and development needs of those undertaking the health checks to ensure appropriate, effective and timely escalation based on the results of the assessment	Individuals with lived experience report an inconsistent approach to annual health checks across the UK. There is limited understanding of which members of the healthcare team are performing the checks, what happens as a result of the outcomes of the checks and how the checks correlate to the levels of health inequality and comorbidities
6. The development of a nurse-led pathway to support the referral and transition from learning disability mental health services for those children and young people with learning disabilities in need of support from mental health services	Practitioners working in child and adolescent mental health services and learning disability report challenges in referring individuals between the two services. The effectiveness of current pathways is unclear. This work will review the current pathways and explore ways to manage transitions of care between the two services
7. The RCN Foundation chair in adult social care nursing will firstly explore where RNLDs and nursing associates in England are working in adult social care across the UK. The study will then explore the phenomenon of RNLDs losing their identity in social care nursing and leaving the Nursing and Midwifery Council register	Policymakers and charities have reported that many RNLDs deregister when working in social care. This work will explore why and the effect this is having on the workforce, with recommendations to prevent this from happening
8. A nurse-led research study to reduce health inequality and enhance health-related quality of life outcomes for people with lived experience of learning disabilities in Wales	Discussions with academics and practitioners in Wales identified challenges specific to this country
9. A nurse-led research study to reduce health inequality and enhance health-related quality of life outcomes for people with lived experience of learning disabilities in Northern Ireland	Discussions with academics and practitioners in Northern Ireland identified challenges specific to this country

experiences. The effects of this approach were significant. The RCN Foundation has learned directly from the perspectives of a range of individuals with lived experience about what is important to them, what their priorities are for nursing care to keep them fit and healthy, and what they consider important to be included in the RCN Foundation's programme.

A sample of the comments from individuals with lived experience of learning disabilities during these discussions is shown in Box 2.

The programme is now in the delivery phase and the voice of individuals with lived experience of learning disabilities continues to be central. They join the selection panels for the research projects and scholarships, asking questions that they have personally developed. They are accompanied by a supporter and reasonable adjustments are in place, including additional time for asking questions and providing feedback to other panel members when making decisions. Adequate breaks are also provided between each interview.

Although the programme is relatively early in its delivery, the contribution of individuals with lived experience has been significant. They bring a unique perspective based on their own experiences which only they can understand and appreciate. This has led the RCN Foundation to approach the programme through a new, unique lens based on the lived experience of individuals.

Inclusive Health programme

The aim and objectives of the Inclusive Health programme are presented in Box 3.

The Inclusive Health programme funds nine research projects and the RCN Foundation scholarship for five RNLDs to undertake an MSc Advanced Practice – Learning Disability where statutory funding is not available. A summary of these research projects is presented in Table 1, along with the rationale for their inclusion.

Impact assessment and evaluation

The effect of the work funded by the RCN Foundation is demonstrated through a bespoke impact assessment framework underpinned by a logic model (Robert 2013, Kekahio et al 2014), which focuses on outputs and outcomes. Research proposals must include the anticipated outputs, outcomes and effect of the work. These are reported against at the end of the study. The RCN Foundation also reports longitudinally on impact metrics at 12 months and three years after study completion, based on the impact assessment framework. A formal evaluation of the Inclusive Health programme will occur when all work is completed in 2027.

Conclusion

People with learning disabilities experience significant and persistent health inequalities, contributing to reduced life expectancy and poorer health-related quality of life outcomes. Addressing these disparities requires a strong, well-supported learning disability nursing workforce equipped with the knowledge, skills and resources to deliver person-centred, evidence-based care.

The RCN Foundation has recognised learning disability nursing as a priority and developed the Inclusive Health programme to support nurses in addressing these challenges. This initiative encompasses nine research projects and advanced practice scholarships, focusing on key issues such as workforce challenges, access to healthcare and the impact of RNLDs in different settings, including social care. A strength of the programme is its co-production approach, ensuring that individuals with lived experience have a central role in shaping research and education.

By strengthening the evidence base, supporting workforce development and advocating for systemic change, the Inclusive Health programme aims to drive long-term improvements in health-related quality of life outcomes and reduce inequalities for people with learning disabilities across the UK.

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