

RCN Foundation Briefing | April 2024

Grant-making programme: Inclusive Health – enhancing the lives of individuals with learning disabilities

Introduction

This briefing provides an overview of the RCN Foundation's grant-making programme on learning disability and learning disability nursing. The *Inclusive Health – enhancing the lives of individuals with learning disabilities* programme will be delivered over a four-year period at a cost of around £360,000.

The landscape for learning disability and learning disability nursing in the UK

A learning disability is a lifelong condition which significantly affects an individual's ability to carry out everyday activities, understand new or complex information and learn new skills (NHS, 2018; Mencap, 2022). There are currently 1.5 million people in the UK with a learning disability which accounts for 2.16% of adults and 2.5% of children (ONS, 2020).

People with learning disabilities:

- Demonstrate greater health needs than the general population, with 50% having at least 1 significant health problem.
- Are 20 times more likely to have epilepsy than the general population.
- Have a higher prevalence of psychiatric illness in children and adults compared to the general population.
- Have higher rates of dementia (22%) than the general population (6%).
- Are likely to have eating, drinking and swallowing difficulties (40%) resulting in recurrent respiratory tract infections.
- Are more likely to have a visual and/or hearing impairment.
- Require greater levels of health promotion to prevent obesity or anorexia. Less than 10% of adults with learning disabilities in supported accommodation follow a balanced diet and engage in exercise.

(NHS, 2018)

Registered Nurses for Learning Disability (RNLDs) are trained to provide specialist support to individuals with a learning disability, as well as their family and other members of the multi-disciplinary team, to maintain positive physical and mental health so that they can lead fulfilling lives (NHS, 2022).

Since 2009, there has been considerable pressure on RNLD workforce capacity, which has seen a fall in numbers by some 43% to 16,840. This compares to 587,885 for adult nurses, 95,485 for mental health nurses and 57,014 for children's nurses (NMC, 2023).

These challenges have been compounded by a significant drop in the number of pre-registration, undergraduate learning disability student nurses across the UK, with applications dropping by 45% between 2016-2019. In 2018, 50% of universities were considering stopping this provision (Council of Deans, 2018).

Addressing the challenge

Within the context of premature deaths, significant health inequalities and limited workforce capacity, the RCN Foundation agreed that learning disability and learning disability nursing would be a priority area for grant-making within its 2018-2023 strategy.

To that end, in 2019, the RCN Foundation commissioned and funded the University of West London to undertake a scoping review to identify learning disability nursing interventions and their impact on the health of people with a lived experience of a learning disability. The findings from the scoping review, alongside a co-production exercise involving key stakeholders which included those with lived experience of a learning disability, led to the development of a grant-making programme to support and strengthen the learning disability nursing profession, and improve care for those they support.

In order to address the health and care challenges faced by people with a learning disability, the RCN Foundation launched a grant-making programme in 2024 entitled *Inclusive Health – enhancing the lives of individuals with learning disabilities*. The aim of the programme is to enable RNLDs to reduce health inequality and enhance health related quality of life outcomes for people with lived experience of a learning disability.

The overall aim will be achieved through the delivery of two objectives:

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

The *Inclusive Health* Grant-making Programme

The *Inclusive Health* grant-making programme will run from 2024-28. It will comprise nine research studies, some of which will be bespoke to the nations of the UK, which will be

phased to take place during the four-year period of this programme. The programme will also include funding for scholarships in Advanced Practice for RNLDs working in social care or across social care and the NHS. Importantly, each research project will involve co-production to include the voice of those with lived experience of a learning disability.

The nine research projects to be funded over the next four years are as follows:

- A comprehensive analysis of the economic case for investing in the RNLD field and the impact this has on patient centred care and health related outcomes across the UK.
- A study to evaluate the impact of the RNLD's contribution to reducing health inequality and premature death for people with lived experience of a learning disability.
- A study to explore firstly where RNLDs and nursing associates (in England) are working within adult social care across the UK. The study will explore the phenomenon of RNLDs losing their identity within social care nursing and leaving the NMC register. The research will examine why this is happening, the impact on the lived experience of service users and carers, and the subsequent effect on workforce capacity within the sector. The study will aim to recommend strategies to address this exodus of RNLDs within social care. This project will be led by the RCN Foundation Chair in Adult Social Care Nursing at the University of Salford.
- A study to analyse and evaluate the impact of the annual health check on reducing health inequalities and premature death for those with a learning disability or autism. The output will be a national, evidence-based model for the annual health check which makes best use of digital technologies for the assessment, record keeping and communication of need. Recommendations will be made for the education, training and development needs of those undertaking the health checks, to ensure appropriate, effective and timely escalation based upon the results of the assessment.
- The development of a co-designed tool to assist people with lived experience of a learning disability to access urgent and emergency care in times of ill health. This would be based upon an analysis of the experiences of those accessing services, learning from these and their suggestions to enhance access along with the impact of the RNLD within these services on health inequality and health related outcome for those with a learning disability.
- The development of a nurse-led pathway to support referral and transition from learning disability provision to mental health services for those children and young people with a learning disability in need of support from mental health services.
- A project in Scotland to develop 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. This will enhance the student experience and retain students on the learning disability undergraduate pathway to grow the learning disability nursing workforce which will ultimately reduce health inequality and improve health related outcomes for people with a learning disability, in remote and rural settings.

- A nurse-led research study in Wales to reduce health inequalities and enhance health related quality of life outcomes for people with lived experience of a learning disability.
- A nurse-led research study in Northern Ireland to reduce health inequalities and enhance health related quality of life outcomes for people with lived experience of a learning disability.

How we will measure the impact of the programme

The impact of the *Inclusive Health* programme will be measured and reported through a number of approaches.

The RCN Foundation Impact Assessment Framework will be used to measure the impact of individual studies. This Framework sets out the anticipated outcomes, outputs and impact to be measured, as agreed with those delivering the project. This is then followed up one year after the end of a study to understand the longer-term impact.

Those undertaking the scholarship programme will be asked to report annually on its impact on their personal and professional development, and their clinical practice. This will be supported by testimonials from individuals with lived experience of a learning disability who are the recipients of care. At the end of their course of study, the scholars will be asked to submit a final report to the Foundation which sets out the overall impact of the programme. They will be asked to share the work from their final major project or dissertation which will be added to the RCN Foundation's Repository following a quality assurance review.

An independent evaluation of the overall grant-making programme will take place once it is fully completed.

Conclusion

The *Inclusive Health* grant-making programme represents the RCN Foundation's firm commitment to supporting and strengthening learning disability nursing and, in so doing, to improving the quality of life and health outcomes for people with a learning disability. We hope that our long-term focus will lead to positive outcomes for people with a learning disability and those who care for them, as well as a bringing greater attention to this important topic.

For further information about the programme, please contact rcnfoundation@rcn.org.uk.