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Adult Social Care Reform: The Cost of Inaction
Submission to the Health and Social Care Committee Inquiry

Evidence submitted by:

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1. Background

- 1.1. The RCN Foundation is an independent charity and grant-maker, whose purpose is to support and strengthen nursing and midwifery to improve the health and wellbeing of the public. We support any current and former nurse, midwife, healthcare support worker, student and nursing associate.
- 1.2. The charity works closely with, but is independent of, the Royal College of Nursing (RCN) and is part of the RCN Group. Our work is delivered through a programme of grants to individuals and organisations focussed on three core areas: hardship, education and career development, and research and innovation.
- 1.3. The RCN Foundation has a long-standing commitment to supporting the adult social care sector. In 2013, the Foundation agreed to adopt social care, as a grant-making priority. This was in recognition that there were a significant and growing number of nurses working within this sector, often in situations where they were isolated and with little access to learning and career development. Equally, it was recognised that they were likely to be developing new innovations and ways of working which could significantly enhance the delivery of care to those receiving it.
- 1.4. This began a long-term commitment to supporting and strengthening nursing in an adult social care setting and improving outcomes for those in their care. With approximately 18,500 separate organisations providing social care services in England, employing around 34,000 registered nurses between them (Skills for Care, 2024), investing in this part of the workforce is vital.

2. Introduction

- 2.1. Inaction on adult social care reform costs lives and the cost of that inaction is being borne by adults using social care and their families.
- 2.2. Individuals with a learning disability experience significant health challenges combined with greater health inequalities, when compared to the wider population ([House of Commons 2024](#)). Health inequalities are defined by the World Health Organization as unjust and avoidable differences in health outcomes across the population and between different societal groups ([WHO 2018](#)). Health inequalities are exacerbated by the deprivation gap which is the difference in life expectancy between individuals who live in the most deprived areas of the country in comparison to those who do not (The King's Fund, 2024). 25% of individuals with a learning disability who died in 2022, lived in the most deprived parts of the country, compared to 10% who resided in the least deprived area ([King's College London, 2023](#))
- 2.3. For individuals with a learning disability, these 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; Alzheimer's Society, 2023; KCL, 2023; Rainer and Abdinasir, 2023; Watkins and Jones, 2024).
- 2.4. In view of this compelling evidence, the RCN Foundation identified Learning Disability Nursing as a priority for its work, continuing its support for adult social care. This also aligned with the strong Equity, Diversity and Inclusion ethos the Foundation applies to all of its work, with the [NHS Race Observatory \(2023\)](#) identifying that the average life expectancy for individuals with a learning disability from Black and Minority Ethnic communities is 34 years old compared to 62 years for people denoted as white. However, in its report, the NHS Race Observatory advises caution in using these figures because of the probable considerable under-reporting of ethnicity in the data sources they employ.
- 2.5. In 2023, the RCN Foundation delivered on its public commitment to the adult social care sector by committing funding to two significant initiatives. First, the Foundation invested £700,000 in the creation of the Chair in Adult Social Care Nursing. This role, which is the first of its kind, represents a critical opportunity to raise the profile of social care as well as to take a strategic lead in shaping teaching, research and clinical practice in this area.
- 2.6. Secondly, the Foundation launched its new grant-making programme entitled *Inclusive health – enhancing the lives of individuals with learning disabilities*. This is a £300,000 research and education programme aimed at addressing health inequalities and premature deaths, and improving quality of life outcomes, for individuals with lived experience of a learning disability through evidence-based, person-centred nursing care. The first study to be funded within this programme was a rapid review to investigate the economic benefits of learning disability nurses in the UK. This research was undertaken by Professor Martin Knapp and his team at the London School of Economics and Political Science.

3. Chair in Adult Social Care Nursing

- 3.1. Professor Clare Pryor at the University of Salford was appointed the Chair in Adult Social Care Nursing in July 2024, alongside Dr Siobhan Kelly (Post Doc Research Fellow) appointed August 2024. The creation of these roles was in recognition of the need to grow the evidence base for excellent provision through national and international research collaborations with academic institutions and key stakeholders within adult social care.
- 3.2. Professors Pryor, Heaslip and Drs Stephens and Kelly are currently undertaking a systematic review of enhanced, specialist, and advanced nursing roles in care homes or charities to understand the landscape of current practice both in the UK and internationally. Alongside this is a concept analysis of the perception and understanding of adult social care nursing amongst and associated health and social care workers. This concept analysis will provide greater clarity regarding definitions of social care nursing, as currently there is limited understanding of social care nursing. The results of both of these research projects will be available in the first quarter of 2025.
4. The economic case for investing in the RNLD workforce
 - 4.1. The study found evidence of the effectiveness of the Registered Nurse for Learning Disability (RNLD) in addressing a number of health and related issues, including reducing and managing obesity, improving sleep, managing constipation, managing behaviour that challenges and improving older people's wellbeing. The review found that RNLDs help to improve access to health screenings as well as support decision-making around consent. They also positively influence the quality and safety of hospital care for individuals with a learning disability across the lifespan. Whilst there are economic consequences of not addressing these issues, the review found little data related to the economic impact of these interventions by RNLDs. Many studies focused on clinical outcomes without providing corresponding economic evaluations.
 - 4.2. However, whilst further work is needed to identify the economic impact of the interventions being undertaken by RNLD, it is clear that no action, or the wrong action, does have economic consequences. Data from ITV News and Mencap in 2024 showed that the NHS spent £534 million on inpatient mental health care for people with learning disabilities and/or autism, even though 41% of people in these hospitals could have had their needs met in the community. The study goes on to highlight that the real cost could be even higher as this figure is for basic costs alone and not additional needs.
5. Conclusion
 - 5.1. Delivering effective and timely care for people using social care leads to good outcomes, promotes dignity and has the potential to make a positive impact on the public purse. Aaron Hume, an Expert by Experience and Learning Disability rights campaigner summed it up at a recent event hosted by the RCN Foundation, when he said, "if you get it right for people with learning disabilities, you get it right for everyone."

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