Rapid review on the economic impact of learning disability nurses in the UK

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Introduction

Learning disability (LD) nurses play a vital role in addressing the complex health and social care needs of individuals with learning disabilities, in pursuit of equitable access to health and social care and to promote better outcomes. Their expertise extends beyond care, involving advocacy, health promotion, and the facilitation of reasonable adjustments within health and care settings. By supporting people with learning disabilities through tailored interventions, they help manage conditions such as epilepsy, mental health issues, and other chronic conditions. LD nurses also work collaboratively with families, carers, and multidisciplinary teams to provide holistic, person-centred care. Their contributions not only have the potential to improve the quality of life for individuals with learning disabilities but also to reduce health

inequalities and enhance the effectiveness of services, making them key to the pursuit of inclusive and accessible health and social care.

The primary aim of this rapid review is to investigate the economic benefits of LD nurses in the UK. This summary presents findings from two workstreams focusing on the benefits of LD nurses and the economic evidence related to their interventions. The insights drawn from various studies highlight the positive impact of nursing interventions across multiple health domains, including obesity management, sleep quality, and family dynamics. Furthermore, the economic implications of these interventions underscore the need for continued investment in LD nursing to enhance health outcomes, improve the cost-effectiveness of services and potentially reduce health and social care costs.

We report findings of two rapid literature reviews, conducted to find economic evidence of LD nurses' societal impact.

Primary review question:

- What are the economic benefits of LD nurses in the UK?

Methods

This summary is based on a rapid review conducted by two independent reviewers. The first reviewer was responsible for examining all ‘grey literature’ related to learning disability nursing, systematically extracting data into an Excel template. The second reviewer focused on database searches, utilising Rayyan for screening abstracts, conducting full-text reviews, and extracting data from the included studies. The review was structured into two consecutive and complementary workstreams:

1. Workstream 1: This workstream assessed the benefits of LD nurses in various health contexts, including obesity, sleep, and behavioural interventions.
2. Workstream 2: This workstream focused on the economic evidence surrounding the health context interventions identified in Workstream 1,

analysing cost-effectiveness and potential savings associated with nursing-led initiatives.

Bibliographic searches

Four bibliographic databases were searched for workstream 1 (Embase via Ovid, PsycINFO via Ovid, MEDLINE via Ovid, and CINAHL via EBSCOhost) and three were searched for workstream 2 (Embase via Ovid, PsycINFO via Ovid, MEDLINE via Ovid), in June and July 2024 respectively. Workstream 1's search strategy was structured around the key terms (learning disability OR learning deficit OR learning problem OR learning impairment OR intellectual disability) AND nurses AND intervention. Workstream 2's search strategy was structured around the key terms ((learning disability OR learning deficit OR learning problem OR learning impairment OR intellectual disability) AND (economic evaluation OR cost-effectiveness OR economic impact OR societal cost) AND relevant key terms for interventions found in Workstream 1's search results. Records were de-duplicated in EndNote. Titles and abstracts were independently screen by one reviewer on Rayyan. We used abstract screening tools for consistency. Uncertainties were resolved in discussion with a second reviewer.

Grey literature searches

Google searches were undertaken in June and July 2024 for workstream 1 and 2 respectively. Workstream 1 search strategy was structured around the strings: ("learning disability nurses" OR "intellectual disability nurses" OR "LD nurses") AND ("economic impact" OR "cost-effectiveness" OR "cost analysis" OR "healthcare costs" OR "economic evaluation" OR "cost-benefit analysis" OR "economic outcomes" OR "financial impact" OR "economic benefit" OR "resource use"). Workstream 2's search strategy was expanded to include key terms related to the specific interventions found in workstream 1 AND (learning disability or intellectual disability) AND ("economic impact" OR "cost-effectiveness" OR "cost analysis" OR "healthcare costs" OR "economic evaluation" OR "cost-benefit analysis" OR "economic outcomes" OR "financial impact" OR "economic benefit" OR "resource use"). The objective was to find reports not arising from the bibliographic searches.

One reviewer screened the first four pages of each set of results using the abstract screen tools.

Results

For Workstream 1, 794 records were retrieved and 10 were included for full text review. For Workstream 2, 405 records were retrieved and 8 were included for full text review. The grey literature search retrieved 268 records for workstream 1, of which 15 were included. For Workstream 2, 465 records were retrieved and 4 were included. The results are organised into the nine identified intervention categories from Workstream 1.

1. Impact on obesity

Obesity is a significant health concern for individuals with learning disabilities, affecting both physical health and quality of life (Public Health England, 2020). Strong evidence from multiple UK-based studies supports the effectiveness of nursing interventions in managing obesity. Specifically, nursing interventions targeting dietary habits and physical activity have been shown to reduce obesity (Jinks et al., 2011). Nurses play a vital role in disease prevention through nutritional interventions, such as dietary planning and weight management (Sheerin et al., 2008). Additionally, health promotion activities conducted by nurses can enhance health screenings and interventions for obesity (Marshall et al., 2003). However, there is no direct economic evidence available regarding these interventions.

Economic impact for LD nurses:

There is strong evidence from multiple UK-based studies demonstrating the effectiveness of interventions for managing obesity in individuals with learning disabilities, yet direct economic data is lacking. Given that individuals with learning disabilities experience higher rates of obesity compared to those without LD, and considering the significant health benefits associated with effective obesity management, further modelling of potential cost savings from nurse-led obesity

interventions is essential. The current annual societal cost of obesity in the UK is estimated at £58 billion (Frontier Economics, 2022), highlighting the potential for nurse-led initiatives to reduce obesity among individuals with learning disabilities and generate substantial societal savings.

2. Impact on sleep

Sleep difficulties are prevalent among individuals with learning disabilities and can significantly affect their overall health and well-being, as well as that of their carers (Bembridge et al., 2022). Moderate evidence from descriptive studies and case studies, primarily from the UK, supports the effectiveness of nursing interventions in managing sleep disturbances in learning disability populations. Specifically, nursing interventions aimed at enhancing sleep knowledge among parents have been shown to increase their confidence in managing sleep problems, resulting in positive effects on children's sleep for some families (Bembridge et al., 2022). A descriptive report of a nursing-led project indicated that 60% of participants felt that the information gained from the workshop had a positive impact on their child's sleep. In addition, LD nurses can conduct sleep assessments based on parent reports and sleep diaries, which might lead to cost-effective referrals (Bull-Tyagi et al., 2017). They also play a critical role in reducing melatonin prescriptions and improving behavioural sleep interventions (Bull-Tyagi et al., 2017). With appropriate training and knowledge, nurses can significantly enhance quality of life for children experiencing sleep problems through the implementation of effective behavioural strategies (Sutton et al., 2010). However, there is no direct economic evidence available regarding these interventions.

Economic impact for LD nurses:

While there is moderate evidence supporting the effectiveness of nursing interventions for sleep management, direct economic data is unavailable. Given the significant health benefits associated with improved sleep, further modelling of potential cost savings from nurse-led sleep interventions could be beneficial.

Poor sleep among the UK’s working population generates an estimated cost of £34 billion annually (Hafner, et al., 2017). However, most existing evidence on nursing

interventions focuses on enhancing sleep in children, with limited research measuring the effectiveness of sleep management for adults in the working population. Consequently, there is insufficient evidence to currently assess the economic impact of LD nurses' interventions on sleep management.

3. Impact on constipation

Constipation is a common yet often underestimated issue among individuals with severe learning disabilities (Cockburn-Wells et al., 2014). Limited evidence highlights the crucial role that LD nurses play in raising awareness and facilitating the treatment of constipation within this population (Cockburn-Wells et al., 2014). Effective management of constipation is vital, and training for carers is essential to ensure appropriate care and interventions are implemented. In addition, there is currently no specific research evaluating the economic impact of managing constipation in this population.

Economic impact for LD nurses:

While the role of LD nurses in managing constipation is recognised, the existing evidence is somewhat limited. Although there is some indication that these nurses contribute to effective constipation management for individuals with learning disabilities, the direct economic impact of their interventions remains under-researched. Given that individuals with learning disabilities are more prone to constipation compared to those without, and considering the substantial costs associated with this condition, further exploration into the economic implications of nurse-led interventions is essential.

Constipation management currently accounts for 10% of district nursing time. National statistics indicate a 40.1% increase in laxative use from 2004 to 2014, with laxative prescriptions costing the NHS £117.5 million in England in 2014 (Public Health England, 2016). Additionally, constipation led to a preventable £71 million in unplanned hospital admissions and generated costs of £162 million for the NHS in 2017–18 (The Cost of Constipation Report, 2019). These figures underscore the potential for nurse-led initiatives not only to improve health outcomes but also to

generate significant societal savings by effectively reducing the incidence of constipation among individuals with learning disabilities.

4. Impact on family dynamics

The role of LD nurses extends beyond direct patient care; they play a crucial part in enhancing family dynamics by addressing the impacts of living with a disability has on family structures. Strong evidence for nursing intervention programmes having a positive impact on both psychological and family functioning outcomes. For instance, a study by Yildirim et al. (2012) found that nursing interventions significantly reduced depression and improved the perception of family functioning among mothers with children with learning disabilities. Additionally, the implementation of a Nursing-Based Model on Activities of Living led to improved care outcomes and increased satisfaction among individuals and families (Mert et al., 2022). This evidence highlights the beneficial effects of nursing interventions on the well-being of both children and their families.

In terms of economic evidence, Bauer et al. (2014) demonstrated that advocacy services for parents with learning disabilities, which include information, guidance, and emotional support, can lead to significant cost savings for social services by preventing crises and promoting better outcomes for both parents and children. Advocacy is essential in prevention and early intervention in safeguarding processes. For parents with a learning disability, advocacy services are invaluable, providing crucial support that helps them navigate complex issues and understand their rights and choices. Although this analysis primarily focuses on advocacy services rather than nursing specifically, it underscores the relevance of advocacy within nursing practise.

Economic impact for LD nurses:

There is strong evidence for the positive effects of nursing interventions on family well-being, particularly within the UK context. The economic benefits associated with advocacy services suggest similar potential for nurse-led interventions. Therefore, further modelling of the economic impact on carers could provide valuable insights.

The mean cost of the advocacy intervention was £3,040 (2010 prices); potential cost savings per case ranged from £720 when considering only the effects on children's social services to over £3,130 when factoring in savings to other public services. Additionally, estimated improvements in quality of life and earnings were valued at an extra £550. The short-term return on investment for advocacy was approximately £1.20 for every £1 spent on child safeguarding activities, rising to £2.40 when societal benefits, such as quality-of-life improvements, are included. Although this analysis primarily focuses on advocacy services rather than nursing specifically, it emphasises the significant role advocacy plays within LD nursing practise.

5. Impact on co-morbidities (epilepsy)

Effective management of epilepsy in individuals with learning disabilities requires specialised nursing interventions to improve quality of life and control seizures. Strong evidence supports the critical role of Epilepsy Specialist Nurses (ESNs) in this context. A study by Pennington et al. (2019) found that the ESN role significantly improved both the quality of life and seizure control among individuals with epilepsy and learning disabilities. In addition, the study identified economic benefits, including a reduction in emergency hospital admissions. Specifically, the intervention associated with an epilepsy nurse competency framework resulted in lower costs per participant. From a health and social care perspective, the intervention led to an average cost reduction of £357 per participant (95% confidence interval: −£986 to £294). From a societal perspective, the cost reduction was even more pronounced, averaging £631 (95% confidence interval: −£1,473 to £181).

Another study evaluated a competency framework for nurses and discovered no significant clinical benefit in seizure severity; however, it suggested potential cost-effectiveness due to reduced support costs (Ring et al., 2018). Specifically, the competency framework led to potential savings of £806 in health and social services, £792 in informal care costs, and £47 in societal costs, primarily through reduced hospital admissions and enhanced quality of life. The incremental cost-effectiveness ratios (ICERs) calculated were £220,000 per QALY from a health and social care perspective and £376,000 per QALY from a societal perspective. These figures indicate that while the intervention may reduce costs, its high cost per QALY

suggests limited economic viability under standard thresholds used in health economics. The findings underscore the importance of integrating specialised nursing roles, such as the ESN, in providing care for individuals with learning disabilities and epilepsy, which can yield both clinical improvements and economic benefits.

Economic impact for LD nurses:

Although there was no evidence on LD nurses, there is strong evidence from the UK supporting both clinical and economic benefits of specialised nursing roles in epilepsy management. A competency framework for nurses in epilepsy and learning disabilities population is cost-effective. However, it is important to note that the existing studies primarily focus on this population served by ESNs and not LD nurses. Further economic modelling based on these studies is recommended to enhance understanding of the cost-effectiveness of nurse-led interventions.

6. Impact on behaviours that challenge

Behavioural interventions by nurses are essential in managing behaviours that challenge among individuals with learning and developmental disabilities. These interventions aim to enhance the quality of life and facilitate better social integration for this population. Strong evidence supports the involvement of nurses in various behavioural and mental health interventions, including therapy, skill development for behaviour management, counselling, stress management, and community integration efforts such as social inclusion and employment support (Sheerin et al., 2008).

Unwin et al. (2017) found that specialist services, including community LD nurses, are effective in managing aggressive behaviour among adults with learning disabilities. Their analysis revealed an average service provision cost of approximately £788 per participant over 12 months, covering direct healthcare expenses and resource utilisation. By managing aggressive behaviour in community settings, these services can reduce emergency care incidents, leading to significant cost savings for health and social services. The study also suggests that increasing the number of community nurses could further decrease costs by promoting

proactive management, thereby reducing reliance on more expensive psychiatric services and medications. Overall, the findings highlight the value of investing in specialist community services to enhance care quality while effectively managing costs.

In another study, Jahoda et al. (2017) evaluated the BeatIt Intervention (behavioural activation), delivered by trained community nurses and allied health professionals. While the intervention demonstrated significant clinical improvements in managing depression among adults with learning disabilities, it was deemed not cost-effective when compared to the StepUp Intervention (guided self-help). The incremental cost-effectiveness ratio (ICER) for BeatIt relative to StepUp was calculated at £385,000 per QALY gained, a figure that far exceeds the standard cost-effectiveness threshold accepted by the National Institute for Health and Care Institute (NICE), suggesting limited economic viability. The analysis indicated that the higher treatment costs associated with BeatIt, despite its potential long-term benefits, overshadowed its clinical advantages.

Ondruskova et al. (2024) found that an adapted version of the Stepping Stones Triple P (SSTP) programme significantly improved behavioural outcomes and was cost-effective compared to usual care for preschool children with moderate to severe learning disabilities. SSTP resulted in a mean cost saving of £1,058 per participant from a health and social care perspective and demonstrated an 89% probability of being cost-effective at willingness-to-pay thresholds of £20,000 and £30,000 per QALY gained. This indicates that SSTP, delivered by trained professionals including community nurses, is a viable option for resource allocation, as it helps parents manage behaviours that challenge and promotes a positive home environment.

Economic impact for LD nurses:

There is strong evidence from the UK supporting both clinical and economic benefits of nurse-led behavioural interventions. These interventions not only demonstrate cost-effectiveness, with potential savings in healthcare expenditure, but they may also positively impact unpaid carers by reducing their need for time off work. By effectively managing behaviours that challenge, these services can alleviate stress on carers, leading to improved quality of life for both individuals with learning

disabilities and their families. Continued investment in such services is essential to enhance care quality while realising these economic and social benefits.

7. Impact on adult health checks

Assessing and obtaining informed consent can present challenges for primary care professionals, acting as barriers for adults with learning disabilities when accessing cervical and breast cancer screenings. Moderate evidence suggests that supporting women with learning disabilities in accessing these screenings involves preparing them psychologically for the procedures through informational and behavioural strategies. Participants in relevant studies indicated that these strategies play an important role in increasing predictability and regulating emotions (Gribben and Bell, 2010).

LD nurses often invest time in building long-term relationships with women, fostering trust and in-depth understanding. They also support colleagues in primary care by contributing to decision-making around capacity to consent and best interests, which can influence women's uptake and experiences of screening (Lloyd et al., 2014; Gribben and Bell, 2010). Research indicates that women with learning disabilities are less likely to access breast screening compared to the general population (Sullivan et al., 2004). Therefore, it is vital to support these women in accessing breast screening.

Furthermore, although adult health checks (ACH) are associated with increased healthcare costs – primarily due to higher resource utilization and referrals – they correlate with reduced unplanned healthcare use, suggesting a proactive management approach. Specifically, individuals with learning disability who did not receive AHCs experienced a significant increase in unplanned healthcare use, including unplanned hospital admissions (0.06 increase; $p=0.018$) and outpatient contacts (0.59 increase; $p=0.002$). Additional research is needed to evaluate the long-term outcomes of AHCs, including their impact on mortality and quality of life, to determine if the financial investment is justified by health benefits (Panka et al., 2019).

Bauer et al. (2019) explored the cost-effectiveness of AHCs for older individuals with learning disabilities, finding that these checks led to a mean quality-adjusted life year (QALY) gain of 0.074 but had a high incremental cost-effectiveness ratio (ICER) of £85,632, making them not cost-effective at typical thresholds. The study suggested that reducing the yearly cost of AHCs from £258 to under £100 could improve their cost-effectiveness.

Economic impact for LD nurses:

There is moderate evidence supporting the effectiveness of nursing interventions in increasing access to health screenings. Strong indications suggest that RN-led care improves long-term outcomes and reduces unplanned healthcare usage; however, current economic modelling shows that AHCs for older individuals with learning disabilities are not cost-effective unless costs are significantly reduced.

8. Impact on hospital care for children and young people

LD nurses play a crucial role in influencing the quality and safety of hospital care for children and young people (CYP) with learning disabilities. Evidence suggests that these nurses significantly enhance care outcomes and overall experiences for this population (Oulton et al., 2019). Improving organisational support for learning disability nursing can further lead to better care and outcomes for CYP with learning disabilities, reinforcing the importance of adequate resources and training within healthcare settings (Oulton et al., 2019). However, there is no direct economic evidence available regarding these interventions.

Economic impact for LD nurses:

There is limited evidence regarding nurse interventions on hospital care for children and young people with learning disabilities. While the positive impact of LD nurses on care quality is recognised, more research is needed to quantify the economic benefits and outcomes of nursing interventions in this area.

9. Impact on older people's wellbeing

The growing needs of older adults with learning disabilities necessitate effective nursing interventions, though more research is required to define the specific roles

that nurses will play in this context (Jenkins et al., 2012). Evidence suggests that nursing interventions can significantly address these needs, enhancing the quality of care and support for older individuals.

In terms of economic evidence, there is currently limited information regarding the impact of nurse-led interventions for older adults with learning disabilities. However, a study conducted in the USA by Marek et al. (2012) found that nurse-coordinated home- and community-based services (HCBS) reduced Medicare and Medicaid costs by an average of $1,592 per month compared to traditional nursing home care over a 12-month period. This highlights the potential cost-saving benefits of nurse-coordinated care in older populations.

Economic impact for LD nurses:

There is limited evidence regarding nursing interventions for older adults with learning disabilities. The economic evidence is limited, particularly in the UK context. Most research in this area comes from the US, indicating a need for further exploration to understand the economic impact of nurse-led interventions and how LD nurses can assume a larger role in supporting this population.

Discussion

There are many system-level barriers that people with learning disabilities face across various life domains, such as education, employment, parenting, and health and social care. LD nurses play key roles in addressing these complex needs of individuals with learning disabilities across various settings and life stages (Northway et al., 2017). LD nurses contribute to managing various health issues within the learning disability population, where there are significant health disparities. They also facilitate access to health and care services, and manage a broad range of tasks, including advanced assessments and care planning (Mafuba et al., 2023).

LD nurses play a vital role in facilitating reasonable adjustments and ensuring peple with learning disability access appropriate services. Their involvement is crucial in

areas such as epilepsy management (Pennington et al., 2019), cancer screening (Marriott et al., 2015), health checks, and end-of-life care (Bailey et al., 2014). By acting as a bridge between patients and services, LD nurses help to ensure person-centred care and improve health outcomes (Brown et al., 2012; Adams & Shah, 2016)

In this study, we sought to identify, appraise, and summarise evidence on the economic case for services, therapies and support provided by LD nurses that address these barriers. The project has shown that LD nurses can effectively manage these health issues, leading to improvements in both health outcomes and quality of life for individuals with learning disabilities. Ultimately, by improving access to health and care services, and optimising health and social care management, LD nurses contribute to closing the gap in health and social care access between individuals with learning disabilities and the general population. This proactive approach not only enhances individual health outcomes but also reduces reliance on more expensive, reactive health and care interventions, ultimately promoting greater equity in health and care access and outcomes.

However, there are major gaps in the available economic evidence in relation to LD nurses. There is a need for more research to establish a stronger evidence base that can inform the economic case for effective interventions and clarify the roles of LD nurses. Moreover, these interventions do not come close to addressing the full span of needs and challenges faced by people with learning disabilities in the UK today. They address only a subset of the needs and preferences of people with learning disabilities and their families.

Greater transparency in the roles of LD nurses can enhance communication, integration within the health and social care system, and ultimately lead to better outcomes (Mafuba & Gates, 2015; Taua et al., 2017). Addressing these gaps is critical for advancing the profession and ensuring that the unique needs of people with learning disabilities are met effectively.

This review has shown that investing in LD nursing interventions could address some of the systemic health inequalities faced by individuals with learning disabilities, particularly through cost-effective care that improves health outcomes

while reducing the strain on health and care resources. Scaling up these services would improve the lives of autistic people while making more efficient use of scarce public and private resources.

The evidence we have summarised in this report is helpful for decision making but it is not perfect. For example, most of the studies we found are of short duration and so miss the potentially greater impacts on outcomes and costs. In some cases, the available evidence was either mixed or modest. For example, advocacy services for parents with a learning disability appear to be both effective and cost-saving, but the evidence comes from a small sample. The gaps identified in our study – such as the need for long-term cost-effectiveness data – offer opportunities for future research funding. By addressing these gaps, the scalability of LD nurse interventions can be further explored, leading to a wider application of successful practices.

There is an urgent need to expand both the quantity and quality of evidence to inform strategic decision-making advocating for the integration of LD nurses into multidisciplinary teams across primary care, community services, and specialist settings. The insights from this research can be used to develop training programs for more nurses in the learning disabilities field, expanding the workforce and ensuring the continuity of high-quality care.

Based on the comprehensive review of evidence, several key actions are recommended to advance the field of learning disability nursing:

1. Leverage existing economic research:

Utilise available economic studies on family dynamics, co-morbidities (such as epilepsy), behaviours that challenge, and adult health checks to model the economic impact of LD nurses in the UK. This will help quantify the benefits of nursing interventions in these areas.

2. Explore broader economic and societal impacts:

Investigate the wider economic and societal implications of effectively managing obesity and sleep disturbances. This should include connecting these findings to the robust evidence supporting the effectiveness of learning disability interventions in addressing these conditions.

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