

# Learning Disability Liaison Nursing Services in South East Scotland: A mixed methods impact and outcome research study

There is significant policy focus on meeting the needs of people with learning disabilities and a drive to support inclusion and to facilitate their use of everyday services. There are clear legal and policy requirements for equal access which include the need for 'reasonable adjustments' to meet individual needs. People with learning disabilities have high health needs that can go unrecognised and unmet, which impacts on their life expectancy as well as quality of life, and means they are likely to be frequent users of general hospital services. Evidence suggests that their experiences in hospital can be problematic and that staff require support to ensure that individual needs are met effectively. This has led to political imperatives to effect long term change in practice and attitudes. One model of support is specialist nursing input in the form of Learning Disability Liaison Nursing (LDLN) services. This briefing outlines the findings from a mixed methods research study that aimed to identify the impact and outcomes of four LDLN Services across South East Scotland.

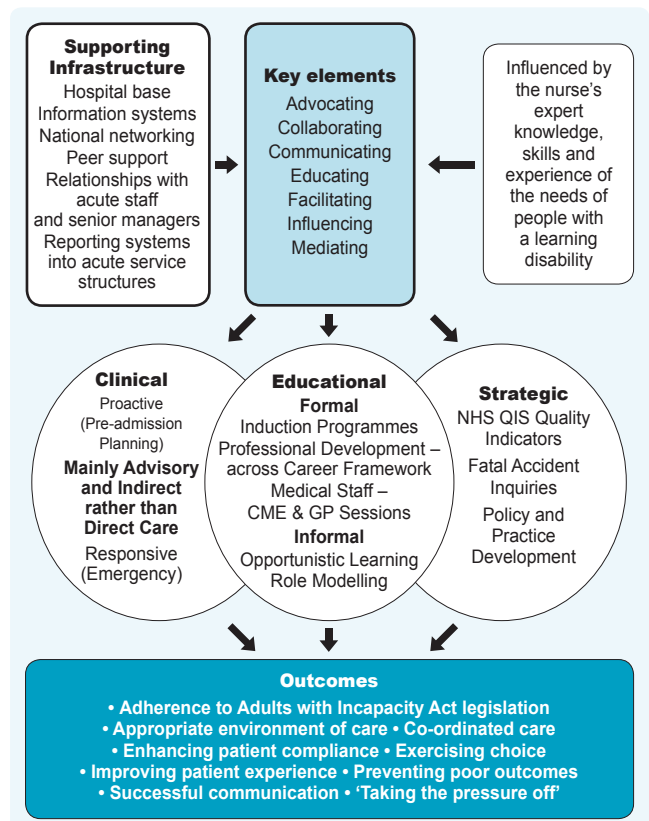


Figure 1: Model of Learning Disability Liaison Services – role, supportive infrastructure and outcomes.

## Key points

- NHS Lothian set up the first Learning Disability Liaison Nursing Service in 1999 and they now exist in the majority of Scottish Health Boards.
- This is the first study to examine LDLN services from a range of stakeholder perspectives and provides evidence of the impact and outcomes.
- The findings are important for service providers, commissioners and planners seeking to respond to policies that demand improvement in general hospital care provided to people with learning disabilities.
- The findings demonstrate that the LDLN role is complex and impacts on (i) clinical care, (ii) education and practice development and (iii) strategic developments.
- The liaison nurses play an important role in raising the profile and status of people with learning disability in general hospitals and the service is highly valued by all stakeholders.
- Their expert knowledge and skills impact on the development of effective systems and processes and improving the patient experience.
- There is a need to take account of the complex and multidimensional nature of the LDLN role and the possible tensions that can exist between achieving clinical outcomes, education and practice developments and strategic initiatives within the resource allocated to each service.



## Background

Two Government reviews have made an important contribution to the care people with a learning disability receive in Scotland: *The Same As You? A Review of Services for People with Learning Disabilities* (Scottish Executive 2000) and *Promoting Health, Supporting Inclusion: The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities* (Scottish Executive 2002). The second report highlighted the role that all nurses and midwives have in ensuring that the needs of people with learning disabilities are met. One recommendation was the need to develop and establish liaison services and as a result LDLN services are being developed across the UK.

The Mencap report *Death by Indifference* (Mencap 2007) put the spotlight on system and service failures in general hospitals and has given renewed focus on issues of equity, safety, communication, capacity, consent and the protection of vulnerable people. In Scotland the quality of healthcare services is very much driven by quality indicators, and the national body NHS Quality Improvement Scotland (QIS) has published specific requirements regarding access to and provision of healthcare for people with a learning disability that have led to national inspections (NHS QIS 2004).

## The study

The study was conducted between June 2008 and November 2009 and formed part of the NHS Lothian Health Services Research Programme funded by the Chief Scientist Office, with additional funding provided by NHS Forth Valley. The aim of the research was to identify and explore the impact of LDLN services in NHS Lothian, Forth Valley, Borders and Fife on the outcomes for people with learning disabilities attending for general hospital care. The research questions were: -

1. What are the core elements and dimensions of the four different LDLN services?
2. What are the different stakeholders views of the LDLN services and the impact on outcomes of care?
3. What elements of the LDLN service are viewed as being effective in supporting healthcare professionals, people with learning disabilities and their carers in general hospitals?

There were two key aspects to the study.

### 1. Liaison nurse activity

The liaison nurses collected audit data on all their referrals over an 18-month period to look at:

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| <ul style="list-style-type: none"><li>• Demographic profile</li><li>• Reasons for and sources of referrals</li><li>• Number of contacts by the Liaison Nurse for each type of referral</li></ul> | <ul style="list-style-type: none"><li>• Nature of interventions by the Liaison Nurse</li><li>• Range of additional health-care professionals involved in the care episode</li><li>• Length of active care episodes</li></ul> |
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## 2. Stakeholder views

85 people were involved in either focus groups or semi-structured interviews and these included adults with a learning disability (5), carers (16), primary care (39) and general hospital (19) staff from all disciplines and the liaison nurses themselves (6).

## The findings

### A brief demographic overview

Over the 18 month period, 323 referrals were received by the four LDLN services. 53% were male and the average age was 46. Of the referrals 55% were emergency or unplanned admissions. The reasons for admission closely match the recognised health profile of this population with 14% being neurology, 10% gastrointestinal, 9% to combined assessment areas, 8% to orthopaedics and 8% to respiratory services. Of the referrals 14% were not previously known to specialist learning disability services. In 65% of the referrals the LDLN was involved in working with 3 or more stakeholders or agencies.

### What the Learning Disability Liaison Nurses said

All of the liaison nurses had extensive knowledge, skills and experience of working with people with learning disabilities across the spectrum of needs. They saw this expertise as being essential in enabling them to influence colleagues, inform treatment and care issues and ensure that reasonable adjustments to care were made. Developing and sustaining effective communication networks and being visible within the hospitals were particularly important but also quite challenging to sustain, given clinical pressures and staff turnover.

The liaison nurses were clear that their role was primarily about facilitating access to health care. They were very much concerned with protecting the rights of individuals, enhancing care and treatment experiences and instilling confidence in general hospital professionals. They used their expertise in areas such as patient and environmental assessment, providing advice and resources to improve communication and supporting decision-making. Managing the expectations of the different stakeholders (particularly carers and general hospital staff) was a core dimension of the role and demanded experienced communication and negotiation skills. The nurses emphasised that their role was very much focussed on complementing and enhancing the skills of general hospital professionals rather than delivering care themselves, thereby developing internal capacity to respond to the needs of people with learning disabilities more confidently.

### The elements of the Liaison Nursing Service

Three core elements were identified by a range of stakeholders: clinical care, education and practice development, and contributing to strategic initiatives.

## **Clinical care**

The participants saw the clinical aspect of the liaison nursing service as key to its effectiveness with three activities being seen as having a direct effect on patient outcomes:

- a) facilitating communication across and outwith the hospital;
- b) assessing care needs and advising on specific requirements including behaviour management and communication techniques;
- c) promoting and ensuring effective coordination of care.

The liaison nurses were seen as an important bridge between the patient, their carers, primary care, specialist learning disability health services and colleagues in general hospitals, such as charge nurses, nurse specialists, secretaries, discharge planners and medical staff. The provision of advice and support to wards and departments was seen by many as 'taking the pressure off' the care setting. The liaison nurses focused on risk management when they recommended individualised care approaches and frequently supported staff to make adjustments to routine practice that ordinarily would have been seen as potentially unsafe, but were well-planned, agreed and appropriately resourced.

## **Education and practice development**

The liaison nurses undertook a range of education and practice development activities in order to enhance the knowledge, skills and attitudes of general hospital staff. They contributed to organisational induction and CPD sessions on issues such as the needs of people with learning disabilities, health profile and presentation (including the potential for diagnostic overshadowing), consent and capacity and the Adults with Incapacity (AWI) Act. In addition, informal opportunistic '5 minute' education sessions were frequently provided in clinical areas, usually in response to a specific patient care issue (for example 'what is autism?' and 'how might it affect this individual in this ward?'). Education sessions were provided for wards, teams and departments on an ad hoc basis. Additionally the liaison nurses contributed to undergraduate education programmes and provided practice placement experience for student nurses.

## **Strategic developments**

The liaison nurses were involved in a wide range of initiatives relating to organisational and strategic developments and were seen to have a positive influence on developing and improving overall services. They were viewed by carers and professionals alike as 'credible ambassadors' for people with a learning disability. The existence of the NHS QIS Quality Indicators for Learning Disability and subsequent inspections were a clear driving force for the organisations, as was the need to respond to

recommendations from two high profile fatal accident inquiries. Once embedded in their roles, the liaison nurses were recognised as being a significant resource to contribute to or lead on the development of policies, procedures and care pathways. Specific examples include the development of a palliative care checklist, implementation of a maternity care pathway and environmental audits to consider the needs of people with a learning disability. Disseminating and sharing good practice around issues such as the AWI Act and capacity to consent to treatment was recognised by many stakeholders as a positive contribution with clear impact on practice.

## **The stakeholder views of what works**

Stakeholders emphasised the clinical aspect of the liaison nursing role in particular their ability to promote effective communication across complex care systems and coordinate the care journey. Their involvement in the care of people with very complex care needs was appreciated and was seen to draw on their expertise, knowledge and skills. It was clear that their role in pre-admission planning was key and many recognised that it helped ensure investigations and procedures took place, and supported patient compliance with treatment and medication. Providing additional support for families and carers during a vulnerable period was valued, particularly their ability to make recommendations for adjustments to care. Acting in an advocacy role was seen as important and there were many examples cited where this had facilitated patient choice and autonomy.

## **The outcomes influenced by the Learning Disability Liaison Nursing Services**

Nurses, doctors, speech and language therapists and carers put forward numerous examples of individual patient outcomes that were directly influenced by the liaison nurses. These included co-ordinated care, successful investigations and treatment, preventing challenging behaviour, increasing staff's confidence, fostering autonomous decision making and ensuring compliance with AWI legislation. One doctor went as far as to suggest that the liaison nurse had been instrumental in preventing an avoidable death. For the liaison nurses their main criteria for a positive outcome was that a patient and/or carer had a positive experience and viewed their next hospital attendance as a good thing.

## **Conceptual Model of Impact of the Learning Disability Liaison Nursing Services**

Data from both the quantitative and qualitative elements of the study have led to the generation of a conceptual model (Figure 1, page 1) that outlines the three dimensions of the role, the supportive infrastructure needed to support the nurses in the key activities and the principle outcome for patients, carers, professionals and the organisation as a whole.

### Three recommendations:

1. Learning Disability Liaison Nursing services should be developed in areas where they do not already exist.
2. Learning Disability Liaison Nursing services need to be regularly reviewed, resourced and developed to respond to changing demographics of the population and to health and social care service redesign.
3. The LDLN resource should be targeted at specific clinical areas within general hospitals to achieve maximum impact and person-centred outcomes.

While this paper summarises the important themes and significant findings from the study, more detailed results and examples will be disseminated in the future by:

- Publications in peer-reviewed research journals.
- Presentations at conferences aimed at clinicians, educators, researchers, commissioners and service planners.
- Publication of a practice guide for developing a learning disability liaison services.

### References

Mencap (2007) *Death by Indifference*. London: Mencap

NHS Quality Improvement Scotland (2004) *Quality Indicators for Learning Disabilities*. Edinburgh: NHS Quality Improvement Scotland.

Scottish Executive (2000) *The Same As You? A Review of Services for People with Learning Disabilities*. Edinburgh: The Stationery office.

Scottish Executive (2002) *Promoting Health, Supporting Inclusion: The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities*. Edinburgh: The Stationery Office.

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