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Learning Disability Liaison Nursing Services in South East Scotland



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Background

It has long been recognised that people with a learning disability have different and greater health needs than the general population. These needs more commonly 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. NHS Lothian was the first of the Scottish Health Boards to establish a Learning Disability Liaison Nursing (LDLN) Service in 1999, and the last 10 years have seen the majority of other health boards in Scotland establish similar services.

Aims

This study aimed to investigate the impact of the LDLN Services in 4 health boards (Lothian, Fife, Borders and Forth Valley) in South-East Scotland 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?

Methods

The study 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 study was given ethical approval by Edinburgh Napier University Research Ethics Committee, after Scotland A Research Ethics Committee had deemed the study to be service evaluation. The four regions' research and development offices also granted management approval.

The study involved quantitative and qualitative data collection between June 2008 and November 2009. Each liaison nurse recorded the following data:

- Demographic profile
- Reasons for and sources of referrals
- Number of contacts by the Liaison Nurse for each referral
- Nature of interventions by the Liaison Nurse
- Range of additional healthcare professionals involved in the care episode
- Length of active care episodes

Additionally, patients, carers and staff with whom the liaison nurses had had contact were asked if they would be willing to be interviewed as part of the study. 85 people were subsequently involved in either focus groups or had a semi-structured interview with a member of the research team. Of the 85 participants, there were 5 adults with a learning disability, 16 carers, 39 primary care and 19 general hospital staff as well as the 6 liaison nurses.

Interviews were recorded, transcribed and analysed by the members of the research team. The software QSR NVivo was used to support thematic analysis and provided a systematic tool to ensure valid and evidenced conclusions were drawn from the data.

Results

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. Figures 2., 3. & 4. below show the breakdown of the referrals by type, clinical area and liaison activity.

The Elements of the Liaison Nursing Service.

The range of stakeholders identified three core elements: clinical care, education and practice development and contribution to strategic initiatives.

Figure 1. Conceptual Model of the Learning Disability Liaison Nursing Services

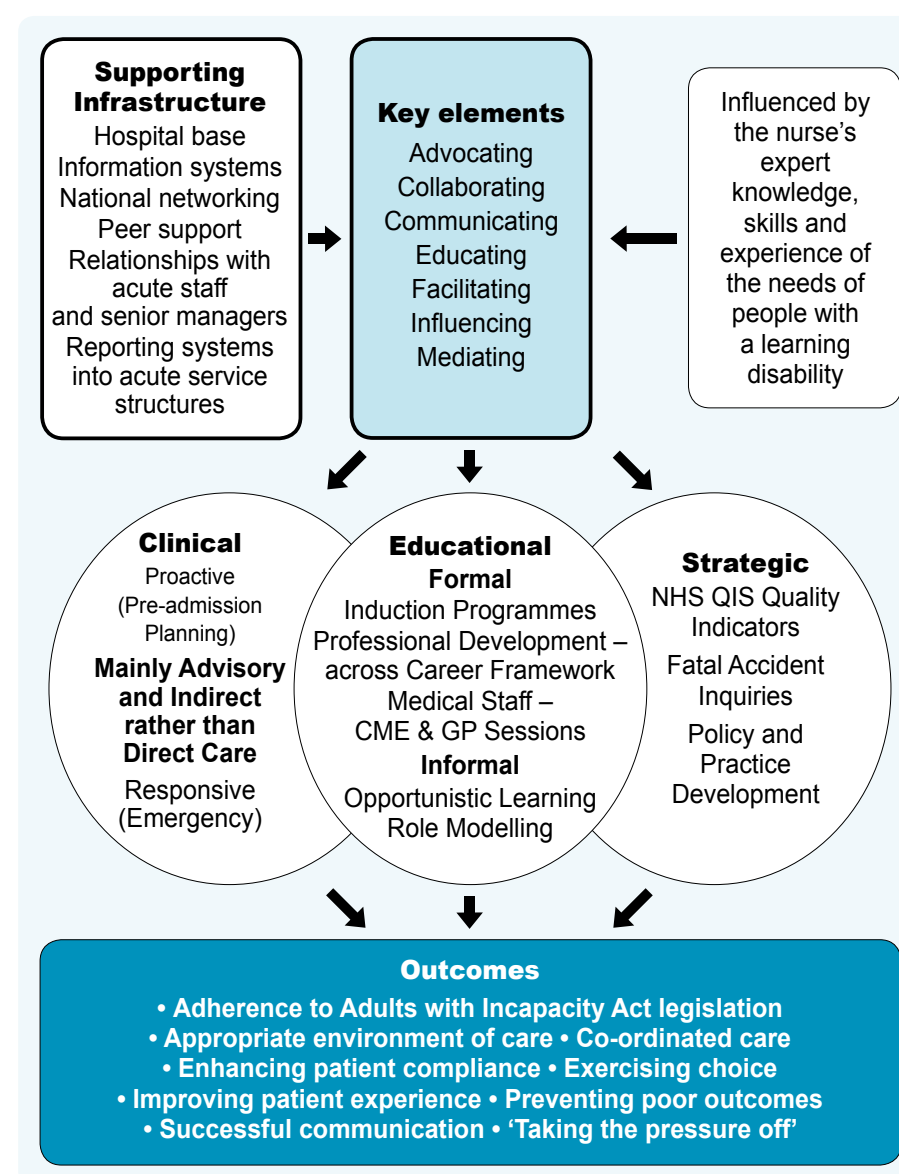


Figure 2.

| Type | Lothian | Fife | Forth Valley | Borders | Total |
|-------------|---------|------|--------------|---------|-------|
| Emergency | 34 | 14 | 80 | 46 | 43 |
| Unscheduled | 17 | 18 | 5 | 2 | 12 |
| Elective | 40 | 21 | 7 | 19 | 26 |
| GP appt | 0 | 0 | 0 | 2 | <1 |
| Outpt appt | 3 | 42 | 5 | 13 | 13 |
| Procedure | 5 | 4 | 0 | 16 | 6 |

Figure 3.

| Clinical Area | Total (%) |
|---------------|-----------|
| neurology | 14 |
| GI | 10 |
| assessment | 9 |
| orthopaedic | 8 |
| respiratory | 8 |
| dentistry | 7 |
| other | 7 |
| colorectal | 4 |
| MRI | 4 |
| urology | 4 |
| unspecified | 3 |
| cardiology | 3 |
| gen medicine | 3 |
| obs & gynae | 3 |
| oncology | 3 |
| ophthalmology | 2 |
| multiple | 2 |
| renal | 2 |
| diabetes | 1 |
| ENT | 1 |
| radiology | 1 |
| no code | 1 |
| self harm | 1 |
| non LD | <1 |

Figure 4.

| Liaison Nurse Activity | Proportion of clients where activity took place (%) |
|--------------------------------|---|
| Information sharing | 67 |
| AWI issues | 41 |
| Discharge planning | 40 |
| Risk management | 39 |
| Behavioural advice | 36 |
| Communication advice | 30 |
| Client support – psychological | 27 |
| Carer support – educational | 27 |
| Carer support – psychological | 27 |
| Bed management | 24 |
| Client support – educational | 23 |
| Client support – physical | 20 |
| Pre morbid baseline | 19 |
| Rearrangement of appointment | 19 |
| Vulnerable adult issues | 16 |
| Eating and drinking guidelines | 13 |
| Diagnostic advice | 10 |
| Other | 5 |
| Arranging visit to ward | 4 |

Discussion

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:

- Facilitating communication
- Assessing care needs and advising on specific requirements and reasonable adjustments
- Ensuring effective coordination of care.

"[The liaison nurse] understands very clearly what his difficulties are and she's been able to put that across to the ... hospital staff when she's been involved in each visit. So the communication has then been excellent which has really helped because [the person] ... become[s] very anxious"

Carer

"I don't think I would have been able to manage any of those patients ... to the same satisfactory conclusion, and ongoing management of their medical conditions without [the liaison nurse's] input."

Hospital Consultant

Education and practice development

Activities focused on enhancing the knowledge, skills and attitudes of general hospital staff. This included:

- Organisational induction
- CPD sessions - health profile, presentation and potential for diagnostic overshadowing
- Consent and capacity and the Adults with Incapacity (AWI) Act
- Opportunistic '5 minute' education sessions in clinical areas
- Undergraduate education programmes and practice placement experience for student nurses

"...the contact I've had with the liaison service makes me more willing to consider what can be done to allow that patient more autonomy in this decision..."

Hospital Staff Nurse

Strategic developments

The Liaison Nurses had significant input into organisational and strategic developments as driven by the NHS Quality Improvement Scotland indicators for learning disabilities including:

- Development of a palliative care checklist
- Implementation of a maternity care pathway
- Dissemination of information on Adults with Incapacity legislation

"I think the biggest part of [the job] should be about ... strategic [developments]"

Care Provider

Outcomes

The various stakeholders described a range of positive individual outcomes for people with a learning disability, as well as strategic and organisational benefits. 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.

"I think that patient would very likely not be alive anymore if [the liaison nurse] hadn't had input into the management."

Hospital Consultant

"[With] a child or an adult who previously had difficulty in accessing the serviceyou can provide the same standard of care, the procedure can be done and they can be discharged..."

Liaison Nurse

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.

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