Learning Disability Liaison Nursing Services in South East Scotland:

A mixed methods impact and outcome research study

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EXECUTIVE SUMMARY

Objective: To explore and identify the impact of Learning Disability Liaison Nursing (LDLN) Services in NHS Lothian, Forth Valley, Borders and Fife on the healthcare experiences of people with a learning disability attending for general hospital care.

Design: A mixed methods design was employed that included analysis of all referrals to the four liaison services over an 18 month period and semi-structured interviews with key stakeholder groups who had all had contact with the Liaison Service.

Participants There were 323 individual referrals to the four liaison services over the 18 month period. 85 people across the 4 health boards were involved in either focus groups or semi-structured interviews and these included adults with a learning disability (n=5), carers (n=16), primary care (n=39) and general hospital (n=19) staff from all disciplines and the liaison nurses themselves (n=6).

Results: Referral patterns demonstrated strong association to the known distinct health needs of the learning disability population (e.g. gastro-intestinal, respiratory and neurological conditions). The LDLN role is complex and impacts on (i) clinical care, (ii) education and practice development and (iii) strategic developments. The Learning Disability Liaison Nurses (LDLN) primarily focused on information sharing and other indirect aspects of patient care, rather than delivering direct care. Key aspects of the LDLN role that led to positive outcomes for all stakeholders included Adults with Incapacity issues, fostering reasonable (and achievable) adjustments to care, augmenting communication and acting as a role model.

Conclusions: The LDLN services in this study were highly valued by all stakeholders through contributing to achieving person centred outcomes. The liaison nurses have an important role in raising the profile and status of people with a learning disability in general hospitals. Their expert knowledge and skills impact on the development of effective systems and processes and contribute to 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 organisational strategic developments within the resource allocated to each service. The results from this study highlight the importance of the ongoing development, promotion and awareness of the LDLN service and the challenges in delivering the complex elements of the role.

The Research Team

The research was undertaken by the Lothian Learning Disability Research Group which involves collaboration between The Centre for Research and Families and Relationships (CRFR), University of Edinburgh, The Faculty of Health, Life & Social Science, Edinburgh Napier University and NHS Lothian.

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1. BACKGROUND AND LITERATURE REVIEW

People with a Learning Disability and General Hospital Care

There has been a clear UK policy focus on the needs of children and adults with a learning disability with a move to ensure that services are person-centred and promote inclusion and equality (Scottish Executive 2000, Department of Health 2001, Welsh Assembly 2002, Department of Health, Social Services and Public Safety 2004, Department of Health 2009a). It is recognised that people with a learning disability experience considerable health inequalities when compared to the general population. There is evidence of a different pattern of disease, with high levels of health needs going unmet (Beange et al. 1995, Cooper et al 2004, NHS Health Scotland 2004, Jansen et al. 2005, Alborz et al. 2005, Cooper et al. 2007, Van Schrojenstein Lantman-de Valk & Walsh 2008, Parliamentary and Health Service Ombudsman 2009, Department of Health 2009b). The high levels of unmet and untreated health needs have been linked to the increased mortality experienced by this group, much of which may be preventable (Patja 2000, NHS Health Scotland 2004, Disability Rights Commission 2006, Department of Health 2009b).

As a consequence of their significant health needs, people with a learning disability are high users of general and specialist health and social care services (Glendinning et al 2001, NHS Health Scotland 2004), including general hospital services (Brown 2005, Gibbs et al. 2008). Epidemiological studies present evidence of differing patterns of use of secondary healthcare services compared to those of the general population, which is seen to have implications for organisation of care and interfaces between acute and primary care services (Morgan et al 2000, Cooper et al 2004, Balogh et al 2005, NHS Quality Improvement Scotland 2006). Specific risks for people with a learning disability associated with general hospital care were identified by the National Patient Safety Agency (2004) and included communication and capacity to consent to treatment issues, risk of choking and aspiration and co-morbid health issues (National Patient Safety Agency 2004). Ineffective communication and lack of information sharing have been viewed as significant contributory factors to the fatal outcome for people with learning disability receiving general hospital care (Mencap 2007, Patrick & Smith 2007, Department of Health 2009b). Further evidence suggests professionals responsible for their care may have limited education and experience of working with this group which impacts on their ability to assess and identify their health needs effectively and enable equal outcomes (Slevin 1995, Shanley & Guest 1995, Slevin & Sines 1996, Bond et al. 1997, McConkey & Truesdale 2000, Philips et al. 2004, Sowney & Barr 2007, Gibbs et al. 2008).

Studies investigating the experiences of adults with a learning disability themselves in general hospitals have found a wide range of interrelated problems, including those of communication, fear and practical difficulties such as getting lost, or not understanding unwritten hospital ‘rules’ (Gibbs, 2001). To address the distinct needs of this population, service models are now emerging that seek to provide additional support for people with a learning disability in the general hospital environment and throughout their care journey (Brown & MacArthur 1999, Brown & MacArthur 2006, Gibbs et al 2008). One such model involves the appointment of Learning Disability Liaison Nurses, who are experienced nurses with a learning disability qualification and work exclusively to support people with a learning disability and their families through hospital admission and attendance. This service was first introduced in Lothian in 1999, and following endorsement in a number of national strategies (Scottish Executive 2002, Department of Health 2009b) has subsequently been developed throughout the UK. Whilst there is anecdotal evidence of the benefit of such services, to date, there has been no research to examine the impact they have for patients, relatives and health care professionals.

2. AIMS

The aim of the study was to explore and identify the impact of Learning Disability Liaison Services in NHS Lothian, Forth Valley, Borders and Fife on the healthcare experiences of people with a learning disability attending for general hospital care.

Research Questions

1. What are the core elements and dimensions of the 4 different LDLN Services in Scotland?

2. How do the different stakeholders view the LDLN Services and what are their criteria for evaluating the outcomes of a care episode?

3. What elements of the LDLN Service are viewed as being particularly effective in supporting healthcare professionals, people with a learning disability and their carers and healthcare professionals in general hospitals?

3. METHODS

There were two strands of data collection, an audit of LDLN activity and qualitative engagement with a range of key stakeholders.

3.1. Liaison Nurse Activity

Activity data were collected by the participating liaison nurses over an 18 month period between July 2007 and December 2008 following initial testing of data collection methods by the Learning Disability Managed Care Network (South East and Tayside). Data included:

- Demographic profile of patients
- 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 patient's care during that admission
- Length of active care episodes

3.2. Qualitative Engagement with Key Stakeholders

Depending on the availability of research subjects and individual preferences either semi-structured interviews or focus groups were held with the key stakeholders, as outlined below with respective inclusion criteria. All participants had personal contact with one of the Liaison Nurses.

Group 1 Learning Disability Liaison Nurses from each of the 4 Health Boards

Group 2 Adults with a Learning Disability

- Person with a mild/moderate learning disability and able to take part in focus group/ interview
- Able to give informed consent to participation (with possible input from Speech and Language Therapist)
- Admission/attendance to general hospital within previous 3 months

Group 3 Carers (Family or Paid, of Adults or Children with a Learning Disability)

- Family carer of adult or child with a learning disability who has been admitted to/attended general hospital in previous 6 months.[1]

Group 4 Primary Healthcare Professional who had had contact with an adult or child with a learning disability who had been admitted to/attended general hospital in the previous

[1] There was no specific case matching between any of the groups, although it may have been the case that patients and their respective carers were both interviewed and that professionals who had been involved in their care were also included.

6 months (Members of the multi□professional Community Learning Disability Teams (CLDT), GPs)

Group 5 Secondary Healthcare Professionals (General Hospital Staff – all disciplines)

- Professional input in care of patient with a learning disability admitted to/attended general hospital in previous 6 months

3.3 Ethics and Research Governance

The Scotland A Research Ethics Committee deemed that this study constituted service evaluation and, therefore, in their opinion did not require ethical approval. NHS Lothian Research and Development Office did consider the study to be research and it, along with the other 3 health boards granted management approval and awarded an honorary contract for the research assistant. Given the potentially sensitive nature of the study and inclusion of vulnerable adults, the research team submitted the proposal to Edinburgh Napier Research Ethics Committee where it was given approval.

3.4 Recruitment

With the exception of the LDLNs, there was a flexible approach to recruitment using convenience sampling. There was some risk of bias in the recruitment of participants as the LDLNs providing the service were involved in the initial recruitment stages. The nature of the project was such that this was viewed as the most appropriate way by the research team to identify potential participants. Following the initial recruitment stage, the Liaison Nurses took no part in participant contact, data collection or analysis.

Adults with a learning disability, who had had direct contact with a liaison nurse, and who were judged to be capable of consenting, were approached by the LDLN with whom they were familiar and were given information about the study that included an invitation to make contact with the research assistant. Carers (family or paid) of adults or children with a learning disability were approached in a similar manner.

Primary care healthcare professionals were recruited directly by the research assistant from members of the CLDT. GPs that had had contact with the LDLN were approached by the relevant LDLN. Practice Managers or Learning Disability Liaison contacts in GP practices were also contacted by either email or letter, with the aim of recruiting further GPs. Amongst secondary healthcare professionals, ward staff that had had direct contact with the LDLN were approached by the LDLN. In addition, the Charge Nurses and multi□disciplinary leads in clinical areas where the LDLN had significant contacts were approached by the Research Assistant and asked to identify any potential participants from their staff teams.

All participants received an information sheet outlining the project and had the opportunity to ask questions. Dr Siobhan Mack, a Specialist Speech and Language Therapist adapted the information sheet to make it accessible to service users. An audio version was also available. Written consent was obtained from all participants.

The recruitment of participants for each stakeholder group in each Health Board area is presented in Table 1 and the breakdown of healthcare professionals in Table 2:

Stakeholder Groups	Health Board				Total
	NHS Lothian	NHS Fife	NHS Borders	NHS Forth Valley	
Adults with Learning Disabilities	3	0	1	1	5
Carers	7	5	2	2	16
Primary Healthcare Professionals	15	8	11	5	39
Secondary Healthcare Professionals	13	2	3	1	19
Liaison Nurses	3	1	1	1	6
Total	41	16	18	10	**85**

Table 1: Research Participants by Stakeholder Group and Health Board

Professional Group	Health Board				Total
	NHS Lothian	NHS Fife	NHS Borders	NHS Forth Valley	
Hospital Doctor	3	1	0	0	4
Hospital Nurse	9	1	3	0	13
Health Care Assistant	1	0	0	0	1
Dietitian	0	0	0	1	1
GP	2	0	0	1	3
Learning Disability Nurse	7	5	5	0	17
Physiotherapist (Learning Disability Service)	1	1	1	1	4
Occupational Therapist (Learning Disability Service)	0	0	1	0	1
Speech and Language Therapist (Learning Disability Service)	4	1	1	1	7
Psychologist	0	1	1	0	2
Psychiatrist	0	0	1	0	1
Social Worker	0	0	1	0	1

Table 2: Healthcare Professionals by Health Board

3.5 Data Analysis

The data were analysed in 2 stages. Stage 1 involved the liaison nurse 18 month activity data which was analysed using SPSS 17.0 and identified the demographic profile, reasons for and sources of referral, numbers of contacts made by the Liaison Nurse for each referral, the nature of the interventions provided by the Liaison Nurse, the range of additional healthcare professionals involved in the care episode and the length of activity of care episodes.

Each focus group or interview was digitally recorded and transcribed verbatim. In Stage 2 each transcript was analysed and coded by at least two members of the team to ensure agreement of the coding scheme. Findings were discussed with the whole team to ensure consistency. The LDLN scripts were deliberately coded last, in order that the development of the codes was directed by the perspective of other stakeholders. Primary coding was under the headings of 'Elements of Service', 'Stakeholder Views' and 'Outcomes' in order to correspond with the original research questions, with secondary and tertiary coding based on emergent themes. An additional primary code was created that focussed on 'Ingredients for Success' in order to make recommendations on how to establish new services. The analysis was managed using the software package QSR Nvivo 8, which is designed to assist with the processes of coding, retrieving and analysing qualitative data. Overall, 44 secondary codes were developed, with a total of 1264 individual references created from the data.

The emergent themes from each of the primary and secondary codes along with the activity data were used to develop the Conceptual Model of the Impact of Learning Disability Liaison Nurses presented in Figure 2 (page 25). Following completion of the analysis, this model was sent to the Liaison Nurses for feedback as a means of confirming content validity, and those that made a response endorsed it.

Table 3 identifies the primary and secondary codes including the number of individual codings attributed to each from the transcripts, which give some indication of the weighting of the issue by the research subjects. This weighting was used to inform the findings and discussion. It should be noted that individual elements of a transcript could be attributed to more than one code as deemed appropriate by the research team.

Table 3: Primary and Secondary Coding of Qualitative Data

Primary Code	Secondary Code	Number of Codings
Element of Service	Individualised Patient Care • Direct (Assessment of care needs, assessment capacity, communication, home visits, pre-admission preparation, support) • Indirect (advice, arranging equipment and staffing, care co-ordination, changing appointments, discharge planning, facilitating access, carer support)	60 64
	Communication	55
	Accessibility	48
	Mediation	36
	Adults with Incapacity	31
	Education and Training	23
	Collaboration	22
	Strategic Developments	21
	Advocacy	16
	Deficits in service	12
	Promoting Access	11
	Expectation Management	9
	Influencing	6
	Staff Support	6
Sub total		**409**
Stakeholder Views	Service Limitations	112
	Challenges for Liaison Nurses	86
	Service Benefits	85
	Service Developments	56
	Communication	52
	Liaison Nurse Skills	27
	Adults with Incapacity	21
	Improving Care	18
	Challenges for Acute Staff	13
	Collaboration	13
	Liaison Nurse Perspective on Acute Hospital	12
	Role of Liaison Nurse	9
Sub total		**426**
Outcomes	Co-ordinated Care (Care co-ordination, discharge planning, preadmission planning, ensuring good outcomes)	105
	Successful Communication	51
	Taking the Pressure Off	47
	Reasonable Adjustments	44
	Preventing Poor Outcomes	29
	Improving Patient Experience	26
	Promoting Awareness	19
	Adherence to Adults with Incapacity Legislation	16
	Strategic Developments	16
	Enhancing Knowledge and Skills	8
	Poor Outcomes	7
		368
Ingredients for Success	Relationships	27
	Liaison Nurse Attributes	15
	Location	6
	Local Champions	5
	Culture	3
	Policy Context	3
	Systems	2
Sub total		**61**
Total		**1264**

4. FINDINGS

4.1 Service Models

Figure 1 summarises the variation in model for each of the LDLN Services in relation to population size, number and type of general hospitals, establishment of liaison service and management arrangements.

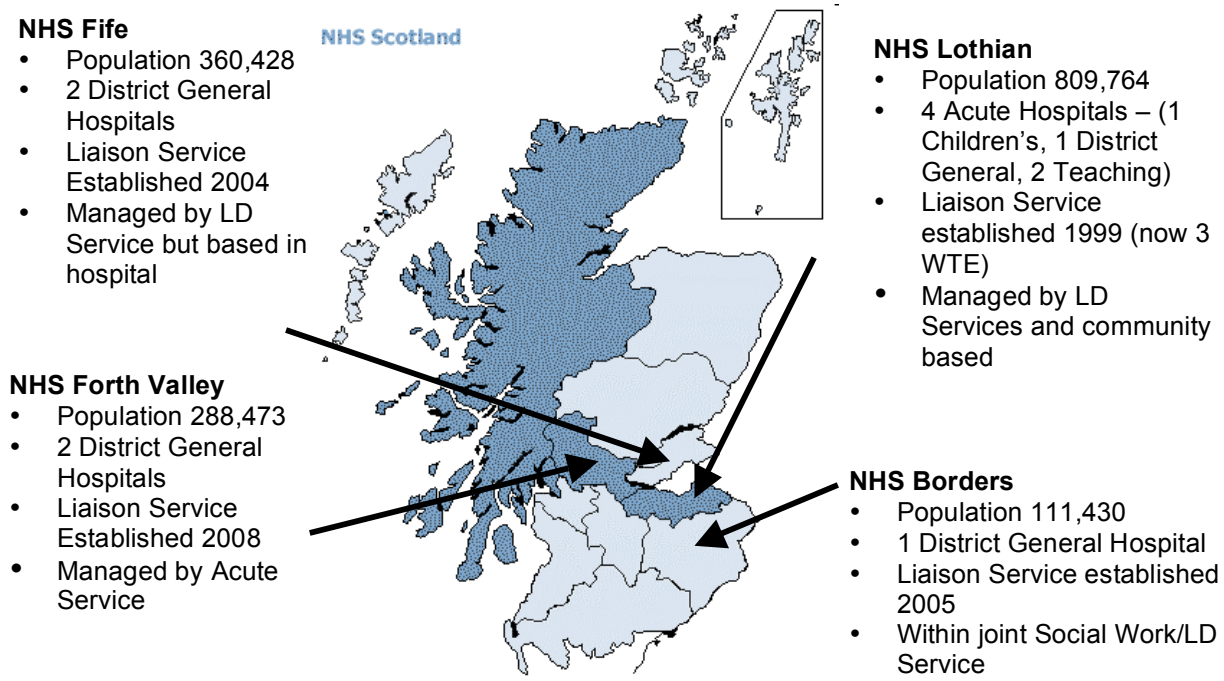


Figure 1: Liaison Service Models in 4 Health Boards

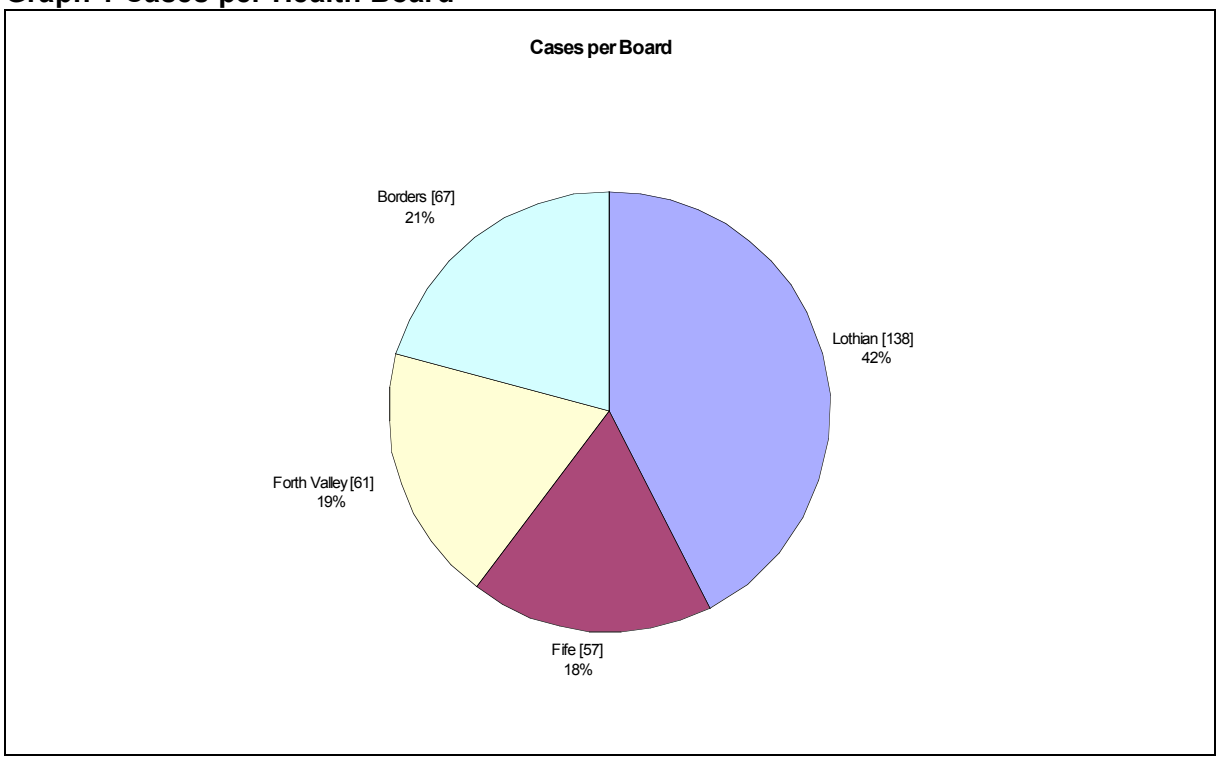
4.2 Liaison Nurse Activity

The data are based on 323 cases, which comprise 18 months of data for each Health Board. Lothian, Fife and Borders data collection ran from July 2007 to December 2008 whereas Forth Valley data was collected between March 2008 and September 2009, due to the service being newly established in 2008. Unless otherwise stated, results are presented as percentages, rounded to the nearest whole number, and ignoring missing data.

4.2.1 Number of Referrals

Board	Number	Percent
Lothian	138	43
Fife	57	18
Forth Valley	61	19
Borders	67	21
Total	323	100

Graph 1 Cases per Health Board



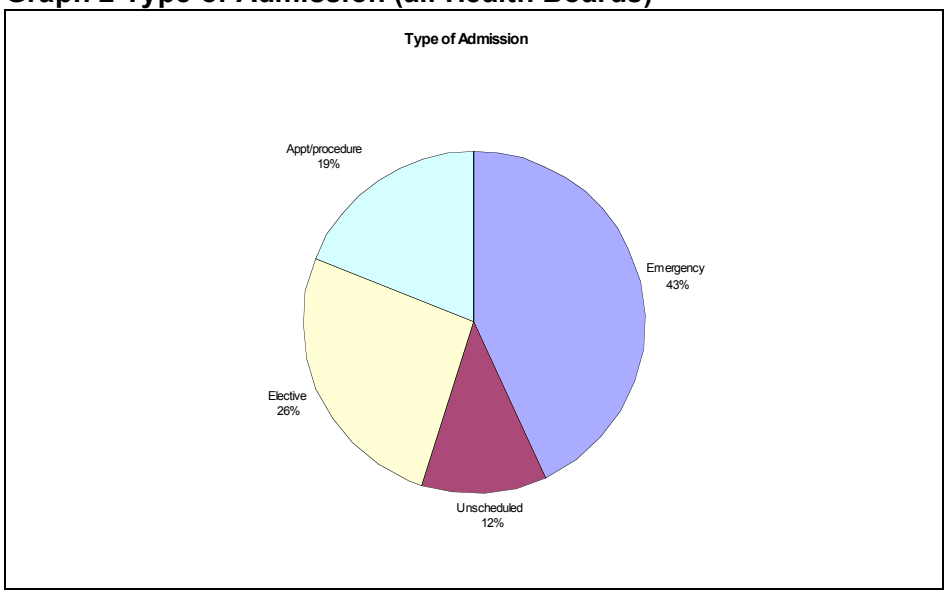
4.2.2 Gender and Age

There were more male patients than female [53% of the total dataset] but individual Boards showed a different gender split, with Borders and Forth Valley having a higher proportion of females. Overall, the age range was from 5 to 87, with a mean of 46.

4.2.3 Type of Admission

The type of admission is shown in Graph 2. This varied widely across the four Boards, possibly reflecting the different models of service as to whether the LDLNs were located in primary or secondary care. Within Lothian, 40% of referrals related to elective admissions whereas in Forth Valley only 7% of referrals were in this category.

Graph 2 Type of Admission (all Health Boards)



4.2.4 Reason for Referral

The most frequent reasons for referral are shown in Table 4. These correspond closely to the research evidence base of the health needs of people with LD as identified in the health needs assessment report (NHS Health Scotland 2004). Some areas varied according to specific service provision, for example there was a relatively high number of MRI patients (recorded separately to neurology admissions) in Lothian reflecting the fact that the Department of Clinical Neurosciences provides specialist services to patients across much of Scotland.

Table 4 Reason for Referral by Health Board

Clinical area	Lothian	Fife	Forth Valley	Borders	Total (as % of all referrals)
Neurology	16	19	15	3	14
Gastro-intestinal	11	9	8	9	10
Assessment	2	12	23	9	9
Orthopaedic	9	4	15	5	8
Respiratory	9	4	12	9	8

4.2.5 Source of Referrals

Across the four Health Boards referrals to the liaison service came mostly from a Community Learning Disability Nurse [19%], a paid carer [17%] or an acute nurse [16%]. However, there was considerable variation within the Boards, for example in NHS Lothian most referrals came from acute nurses [25% of their total], NHS Fife from a Learning Disability Consultant [30%], NHS Borders from paid carers [29%] and NHS Forth Valley from Community Learning Disability Nurses [33%].

4.2.6 Response Times

Response time was within 4 hours in 75% of cases and within 24 hours in a further 19% of cases. The remaining 17 cases [5%] had a response time of over 24 hours: 9 were at the weekend, 5 occurred while the liaison nurses were on leave, 2 required a joint visit with another professional and one had no reason recorded.

4.2.7 Consultation

Liaison activity took place with a wide variety of other people including ward staff, the CLDT and social worker as well as the client and their family and carers. In the majority of cases the liaison nurse had contact with between 2 and 4 people, although one case involved 7 other people or agencies. This activity was not always face to face but referred to liaison in its broadest sense such as advice provided via the telephone and email.

4.2.8 Liaison Nurse Activity

The most common liaison activity was information sharing, which was recorded in 67% of cases, followed by Adults with Incapacity (AWI) issues [41%], discharge planning [40%] and risk management [39%]. By comparison, physical support of patients occurred in only 20% of cases and arranging ward visits took place with only 4% of patients. A full list of activity is shown in Table 5.

Table 5 Liaison Nurse Activity[2] (full data set)

Liaison 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 hospital appointment	19
Vulnerable adult issues	16
Eating and drinking guidelines	13
Diagnostic advice	10
Other	5
Arranging visit to ward	4

4.2.9 Outcome of referral

The outcome of the liaison episode was recorded as 'complete' in 91% of cases. In a further 3% of episodes there was another outcome, mostly cases where it was not clear whether the liaison nurse's involvement had ended, or a series of admissions, or 6-monthly reviews. In the remaining 6% of episodes, the patient died. This represented 20 patients of whom 18 were either emergency or unscheduled admissions.

4.3 Stakeholder Perspectives

The following findings are aggregated across all four Health Boards.

4.3.1 The elements of the Liaison Nursing Service

Three core and complementary elements were identified from the interviews:

1. clinical care,
2. education and practice development,
3. contributing to strategic organisational developments and initiatives.

4.3.1.1 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;

[2] The data represent patient-related episodes and so do not capture the educational and strategic components of the liaison nurse role. These activities were, however, reflected heavily in the qualitative data particularly from LDLNs and secondary healthcare professionals.

c) promoting and ensuring effective coordination of care, thereby ensuring person-centred outcomes.

The liaison nurses were seen as an important bridge between the patient, their carers, primary care staff, specialist learning disability health services and colleagues in general hospitals, such as charge nurses, nurse specialists, secretaries, discharge planners and medical staff.

> *The role of liaison nurse is crucial there from my point of view because that's my link with the hospital*. *[Care Provider]*

> *.. the Liaison Nurse can do quite a bit of getting the two ends of that spectrum to understand each other [Speech and Language Therapist, Primary Care].*

The provision of advice and support to wards and departments was seen by many as 'taking the pressure off' the care setting, thereby acknowledging the wider care issues that can arise in the general hospital setting. The liaison nurses emphasised risk management when they recommended individualised care approaches and frequently supported staff to make adjustments to routine practice. In some cases these adjustments appeared to be potentially high-risk activities that perhaps contraindicated standard policy and practice (for example location of anaesthesia induction and recovery), but were well planned, agreed by all parties and appropriately resourced.

Patients particularly appreciated the approach the liaison nurses took with them, which made them feel valued, and led to improvements in their experience.

> *Because sometimes I feel that before [liaison nurse] was involved you were just pulled aside and that was you. I feel that [liaison nurse] being there has been a lot different now, you get more anything. [Patient 1]*

> *She's a girl… [Liaison Nurse] the type of girl you can talk to. [Patient 3]*

4.3.1.2 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 a learning disability, health profile and presentation (including the potential for diagnostic overshadowing), consent and capacity and the Adults with Incapacity Act. In addition, informal opportunistic sessions were seen as particularly effective.

> *We do feel the one that has great value is the five minute passing conversation you have with people and the educational component that that has of when somebody in a ward with autism. Well, 'what is autism?', and just running somebody through well this is what autism's about, this is the impact on the person, this is the impact on the clinical experience and what you need to do to support that person that's going to be different from what you might be expecting. And I think that five minute conversation with two or three people at the nursing stations, loose and informal, they can ask…as they would say, I can ask a daft question. They're free to do that because it doesn't feel like a teaching thing and that can be a bit more honest education, and hopefully that five minutes has left people with a bit more understanding and it's potentially more value than here's a text book, here's a PowerPoint presentation on the internet, go and read that [Liaison Nurse 1].*

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.

4.3.1.3 Strategic developments

The liaison nurses became involved in a wide range of initiatives related to organisational and strategic developments and were seen to have a positive influence on developing and improving overall services. Collectively the liaison nurses brought a vast amount of knowledge and experience to the role and carers and professionals viewed them as 'credible ambassadors' for people with a learning disability. The existence of the NHS Quality Improvement Scotland Quality Indicators for Learning Disability (2004) and subsequent service reviews were a clear driving force for the organisations, as was the need to respond to recommendations arising from two high profile fatal accident enquiries[3]. 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 Adults with Incapacity Act and capacity to consent to treatment was recognised by many stakeholders as a positive contribution with a clear impact on practice.

4.3.2 Benefits of the LDLN Service

The elements of the services that were highly valued by stakeholders were those that were seen to directly impact on care outcomes. These were seen to draw on their particular expertise, knowledge and skills and primarily focussed on the clinical aspect of the liaison nursing role:

- ability to promote effective communication across highly complex, layered care systems and coordinate the care journey;
- involvement in the care of people with very complex care needs;
- pre-admission planning which helped to ensure that investigations and procedures took place;
- supporting patient compliance with treatment and medication;
- providing additional support for families and carers during a vulnerable period;
- ability to make recommendations for adjustments to care;
- acting in an advocacy role - with many examples cited where the liaison nurses had facilitated patient choice and autonomy.

Where the liaison service was successfully embedded, the liaison nurse was viewed as an integral member of the multidisciplinary team and a significant resource in supporting problem-solving for individual patients.

> *And I think they see you as being part of the team because already it's kind of .. Well I have to keep this person lying flat on his back for the next 24 hours. He's autistic, he's got severe challenging behaviour, how do I do that? Let's phone [Liaison Nurse]. [Liaison Nurse 5].*

The liaison nurses were recognised as having skills in identifying individual patient cues that general hospital staff might not notice or appreciate the significance of.

> *And I think the other thing that's been good, is that they can give us the early warning signs that the patient exhibits if things aren't going well, picking, or whatever they do, you know…[Clinical Nurse Specialist Cardiology].*

Having an understanding of the hospital structures and 'speaking the same language' was seen by primary health care professionals as being a key role of the liaison nurse, particularly where this knowledge was used to escalate concerns.

[3] The Fatal Accident Inquiries related to the deaths of James Mauchland in 1999 and Roderick Donnet in 2007. Further information can be found http://www.scotland.gov.uk/Topics/Justice/law/fatalaccidentinquiries/Recommend

.. it could be problem solving around issues that happen, and she has been mediator as well in terms of, you know, people perhaps not understanding what the problems are and having to sort of take it to a higher level, so speaking to higher levels within the organisation around 'we don't think this is appropriate'. [Occupational Therapist, Primary Care].

Primary care staff felt that the liaison nurses being in a position to understand internal 'politics' was also a significant advantage.

And also they can have a face to face conversation with the staff and know who to talk to, which is the relevant person to say that to and you know who you shouldn't bother saying that to. And we don't have that kind of knowledge of the place where the person is to know them and the people within that [Speech and Language Therapist, Primary Care].

4.4 Reasonable Adjustments

The Equality and Human Rights Commission states:

> 'In most circumstances, health and social care providers must make reasonable adjustments to remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether … As far as possible, the effect of the adjustment should be to make services as accessible to disabled people as they are to other members of the public'.
>
> (Equality and Human Rights Commission 2010).

The Commission defines three categories of reasonable adjustment, all of which are applicable to hospital settings that might be accessed by people with a learning disability. These are:

- Adjustments to physical features
- Auxiliary aids and services
- Adjustments to policies and procedures

It was clear that the LDLNs were involved in supporting adjustments in all three areas, with the largest number occurring in the category of 'auxiliary aids and services', the majority of which relate to issues around a patient's communication needs.

.. with John, she brings it down to his level so he can understand what's going on. I have to say, she's really good at that 'cause I've seen her in different settings and [Liaison Nurse 2] actually one of these really good, unique people who can change to suit the needs [Care Provider].

The data also suggest the need for an additional category of adjustment to be considered that acknowledges the impact that the additional behavioural and emotional needs of some people with a learning disability may otherwise have on their success in accessing hospital services. Recognising their behavioural and emotional needs is important, given the high prevalence of behavioural challenges and communication disorders.

..the knowledge that [Liaison Nurse] been able to pass on, that's made a huge difference because .. he's been in and out of hospital over the past year, [Liaison Nurse] understands very clearly what his difficulties are and she's been able to put that across to the ward staff and the hospital staff when he's been involved in each visit. So the communication has then been excellent which has really helped because he does become very anxious at that [Carer].

The diversity of reasonable adjustments facilitated by the liaison nurses was succinctly described by a psychologist.

It could be behavioural, it could be emotional, you know. So she works closely with the staff, so she is predominantly there, although we're linking back and forwards, she's there, supporting the staff to understand that. Or again, environmental. If the person's in a six bedded unit and we feel at that point that person maybe needs some privacy, or dignity as well [Psychologist].

The liaison nurses recognised the fact that when determining what constitutes a 'reasonable adjustment', it is important to consider the pressures and capacity on general hospital services as well as the needs of the patients. Some of the liaison nurse acknowledged that they had not previously appreciated the pressures within the acute services. Therefore, when exploring possibilities for reasonable adjustment they needed to ensure that carers and primary care staff did not have unreasonable expectations.

I had to change some of my beliefs, I think, and actually my attitudes as well, because it's very easy as a community nurse I was constantly saying, 'oh, those people in hospital' – but actually when you went in and saw how difficult their job is you suddenly started to feel slightly guilty about criticising them all the time. [Liaison Nurse 2]

It's just the pressure that's within the acute hospital is very different from learning disabilities and social care staff don't always understand that. You actually have to be in a ward and realise what the staff are actually having to manage. It's daunting and very dangerous in a lot of situations where patient safety's being compromised in a lot of ways, so us coming in with great, wonderful ideas can obviously always be a bit like 'not today thank you!'. [Liaison Nurse 1]

This might, therefore, be described as 'reasonable and achievable adjustment'. Examples of such adjustment are illustrated in Table 6.

Category of Adjustment	Problem	Adjustment	Reported Outcome/Impact
Auxiliary Aid	Lack of accessible information regarding hospital attendance.	Worked with FAIR[4] to produce accessible information.	Accessible information now available about attending clinics, preadmission etc.
Auxiliary Aid	Need for support to understand procedure in order to give informed consent.	Direct individualised support to patient and ward staff.	Patient able to give informed consent.
Auxiliary Aid	Patient anxiety due to poor understanding of hospital care despite ward staff attempts to explain.	LDLN supported ward staff to adjust their communication.	Significant reduction in anxiety.
Policies and Procedures	Patient anxiety due to busy, noisy environment.	LDLN arranged a quiet waiting room.	'Big difference' for patient and carer.
Policies and Procedures	Patient who has difficulty waiting – can cause disruption in clinics.	LDLN dealt directly with clinic manager to arrange first appointment.	Carer satisfaction – as not able to secure first appointments without input from LDLN.
Behavioural and Emotional	Patient who did not interact well with women.	LDLN addressed issues sensitively with staff	Successful in-patient episode
Behavioural and Emotional	Patient with obsession with water – which could cause potential safety risks during inpatient stay.	LDLN worked with ward and estate staff to have water supply temporarily disconnected from single room during admission.	Successful in-patient episode

Table 6: Categories and Examples of Reasonable Adjustment

[4] FAIR Family Advice and Information Resource an information and advice service for people with a learning disability, parents and carers in Edinburgh. www.fairadvice.org.uk

4.5 Perspectives of the Learning Disability Liaison Nurses

All of the liaison nurses had extensive knowledge, skills and experience of working with people with a learning disability 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, thereby enabling person-centred outcomes to be achieved. Developing and sustaining effective communication networks and being visible within the hospitals were particularly important yet challenging to sustain, given clinical pressures and staff turnover.

> *Sometimes you think you've made an inroad and then the next week they don't know who you are. .. And I think that's something that the quicker you get your head round the concept the better … You can sit at your desk with rose-tinted specs on if you like but it is pure hard graft and it's back and back and back. [Liaison Nurse 6]*

The liaison nurses were clear that their role was primarily about facilitating access to health care. They were concerned with protecting the rights of individuals, enhancing care and treatment experiences and instilling confidence in general hospital professionals.

> *Everything we do is about making sure that people with a learning disability are valued and respected and receive the same healthcare as anybody else. [Liaison Nurse 5]*

They used their expertise in areas such as patient and environmental assessment, providing advice and resources to improve communication and support 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.

> *There are times you feel so much like piggy in the middle because each, nurses, care providers, both have valid points and you're stuck there thinking, what do you want me to do? Yeah, I'll just watch the ping pong going back and forward. (Liaison Nurse 2)*

At times it was evident that communication between staff and carers was poor, which had the potential to impact on both parties. In one case the Liaison Nurse acted as intermediary to try and repair the situation.

> *I got a phone call from a care provider saying they had contacted the ward and they got a really snippy nurse on the other end of the phone. So I said, right, I'll go along and see what's happening. I spoke to the nurse, and all I said to her was, I've been contacted by the care provider. Oh, she says, what a horrible care provider I had on the phone. So obviously the two of them had picked the phone up but both of them had perceived the other to have an attitude so the whole telephone conversation was a waste of time. Because the care provider thought she was snippy, she thought they were snippy[Liaison Nurse 3].*

The nurses emphasised that their role was focussed on complimenting 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 a learning disability more confidently.

4.5.1 Challenges for the Liaison Nurses

Whilst in the main the Liaison Nurses were positive about their role and their experience of working within the general hospital setting, they had faced a number of challenges, which they felt impacted on their potential contribution. These challenges were a combination of organisational, operational and attitudinal factors:

Organisational

- A key issue for the liaison nurses was the fact that the electronic patient management systems (such as TRAK) do not have effective alert mechanisms, which would support the flagging of people with a learning disability (both elective and emergency admissions) to members of the multidisciplinary secondary healthcare team. Various approaches had been explored in different Boards in order to address this, however, data protection issues frequently prevented any progress, despite the fact that the liaison nurses and other stakeholders recognised the potential benefits.

- The reality of bed management and patient movement in acute services was an ongoing challenge and attempting to influence the situation for people with a learning disability was seen as an important priority. This was reflected in the activity data, where 24% of referrals involved 'bed management'. One example cited by a liaison nurse demonstrates this clearly:

> *This lady came in, went to Ward [A], was moved to [B] that night, was moved to Ward [C] the next day, was moved from Ward [D] to Ward [E], discharged, came straight back in that afternoon. Went to Ward [F], was moved to Ward [E] and when I went back on the Monday morning she was in the Gynae ward. [Liaison Nurse 5].*

- The liaison nurses often felt that clinical staff had competing priorities when they attempted to engage them in wider initiatives such as the development of care pathways.

Operational

- The location of the liaison nurse posts was seen as important, with a sense that having a permanent hospital base would improve their profile and the accessibility of the service.

- Outside of Lothian the service consists of a 1 WTE in each Board and there is no cover for the liaison nurses if they are on leave, which can lead to disruption of the service.

- Maintaining awareness of the posts and their contribution to care was the most frequently cited as a challenge. This was both an issue at clinical level, particularly affected by staff turnover, and organisational level, for example using the intranet systems, and contact with switchboard and administration staff.

> *There's never going to be a completely robust way of maintaining awareness across all the services. I think the scattergun…we go around doing as much as we can being quite considered. Right, we need to really build up awareness in an area and we'll put a plan into place and put links in. We try it with everything. But we still have people going 'I didn't know you existed!' [laughs]. It's a surprise. [Liaison Nurse 1]*

- All of the nurses saw achieving an appropriate balance between the clinical and strategic elements of the role as a challenge. The three nurses in Lothian, in particular, felt that their strategic input was significant, and whilst it was seen as welcome with the potential to achieve long-term benefits for patients, it reduced their availability for direct patient work.

> *I think that's where it's time pressures, time management. We can't be in two hospitals at one time. We can't be in a meeting with the chief nurse and be on the ward seeing someone. So it's a matter of prioritising really I think for us, and obviously we'll prioritise someone in need over that. [Liaison Nurse 2]*

> *And there's less patient contact because we've gone through the debates ourselves and I think against the organic thing we've become more engrained in services that we get pulled into more of the strategic policy meetings which means*

we do less patient contact. But if we've got a good policy and a good bit of influence that is hopefully going to have a greater impact. So if we can put something in place in A&E so we can't be there for everybody who comes into A&E, we've mentioned out of hours and things, but at least if we can get an awareness and an education and a system in place that there is a great capacity for people to manage people's care without calling in extra resources or advice then that can only be a good thing [Liaison Nurse 1].

- One of the liaison nurses suggested that there was perhaps a need for a lead post that had a specific remit for strategic engagement, with other members of the team specifically focussing on clinical referrals. It was felt that the possibility of a skill mix within such a team, including support staff, should be considered. Liaison nurses in the other Health Boards who had been in the role for a shorter period of time felt that their strategic involvement was still limited.

Attitudinal

- Securing meaningful and sustained focus on learning disability issues at both a strategic and clinical level was sometimes seen as a challenge. One Liaison Nurse felt strongly that quality initiatives, such as environmental audits, should involve people with a learning disability themselves. However, this was not taken forward when suggested to senior nurses.

- One Liaison Nurse reported occasional problems with acute staff not taking ownership for the care of a person with a learning disability, feeling that their care should be supported by learning disability services or the liaison nurses themselves.

4.6 Adults with Incapacity Act

Part 5 of the Adults with Incapacity Act (Scotland) 2000 (Scottish Executive 2000b) addresses Medical Treatment and Research and became the law in 2002. Issues relating to AWI were a recurrent theme throughout all elements of the study. Whilst there were a few examples of good practice, the evidence points to a poor understanding on the part of some general hospital staff, particularly in relation to the issue of Certificate of Incapacity[5] and accompanying treatment plan. One of the liaison nurses described *'shockingly poor bits of practice'* whilst another stated *'It's actually quite worrying I think, the lack of knowledge around the AWI. It's scary'.*

In the course of the interviews different stakeholders revealed a number of examples of poor practice. These included:

- Carers, both paid and family, being asked to sign a consent form, including by consultant staff, despite this being unlawful.
- Investigations and treatments taking place without an incapacity certificate being in place, when the patient was clearly unable to consent.
- Junior doctors signing the AWI certificate without having had any training on the principles of the legislation or capacity assessment.
- Application of only part of the process, for example certification but no accompanying treatment plan
- Lack of awareness that legislation had changed in 2007, in relation to length of validity of the certificate of incapacity. Old certificates were, therefore, still in use.

[5] A medical practitioner who is primarily responsible for the adult's treatment should complete a certificate certifying that in his or her opinion the adult is incapable of making a decision on the medical treatment in question. Registered nurses, dentists and ophthalmic opticians may issue certificates within their own area of competence and following recognised training. Where the medical practitioner complies with the certification requirements set out in section 47 of 2000 Act and completes a treatment plan, he or she then has authority to give what treatment is reasonable in the circumstances provided the intervention represents the least restrictive method and that the treatments involved are the minimum necessary interventions to safeguard or promote the physical or mental health of the adult. http://www.oqps.gov.uk/legislation/ssi/ssi2007/ssi_20070104_en_1

There were also examples of patients' care being compromised or delayed because of lack of planning or communication regarding AWI issues, including patients arriving at the hospital for a routine appointment and being turned away because there was no AWI certificate in place.

One of the general principles of the AWI Act is that, wherever possible, residual capacity should be fostered, and this is a specific area where the data demonstrated that the liaison nurses had a role to play. However, there were two examples where the liaison nurse had specifically worked with patients to do this, but it had been compromised: in one case when it was judged by the liaison and specialist nurses that a patient would have capacity, but required significant time and augmented communication, a doctor proceeded to issue a certificate of incapacity and perform subsequent surgery. In the other, the doctor had assessed a patient as capable and got him to sign consent for cardiac surgery. However, the specialist and liaison nurses subsequently determined that the patient had not understood much of the conversation and had little idea that he was facing major surgery and the possible implications. However, from the doctor's perspective he had successfully secured informed consent.

4.6.1. What LD Nurses can offer

It was apparent that the liaison nurses had a key role to play in this sphere, and the audit data revealed that AWI issues had been an aspect of their involvement in 41% of referrals. They were involved in raising awareness of the AWI Act, both formally in teaching sessions and informally during clinical consultations, and highlighting and resolving the kind of breaches of the legislation outlined above. The liaison nurses supported health professionals, and patients and carers, often speeding up the process and contributing to successful outcomes, including enabling the patient to give informed consent when it had been assumed that they would be incapable. They utilised their skills in a number of ways including:

- Assessing whether patients had understood information when they had been judged to be capable of consenting.
- Role modelling communication techniques to assess understanding.
- Supporting carers at the time of transition from child to adolescent services and helping them understand that their son or daughter did now have the legal status of an adult.
- Discussing consent with consultants and helping them avoid an assumption of incapacity.

The health care professionals recognised the value of having access to the liaison nurses' expertise and saw this as a key supportive role.

> *I think what's interesting to me is the surgeons get very anxious about this. And I would say the one thing that Liaison Service particularly do well is discuss consent with the consultant and the patient, because otherwise I think everyone would get an incapacity one, and that's not necessarily in their best interests, you know. [Hospital Nurse]*

They appreciated being able to discuss issues of risks and benefits, which they found difficult, and being shown how to communicate a simple explanation of how an operation would help. One individual commented that it was useful to be guided on *'at what point you say that understanding is acceptable to consent'* [SH11 – Hospital Nurse].

4.7 Limitations of LDLN Service

The stakeholders identified a number of limitations of the LDLN services, although in the majority of cases these were related to the circumstances of their specific experience of the service, and not a generalised view. Equally, in the majority of cases, the identification of limitations needed to be viewed in the context of an ultimately positive experience for most stakeholders.

Three key themes emerged and stakeholders viewed these shortcomings as being related to the services' resources, rather than a reflection on the practice of individual liaison nurses.

- *Availability*: the fact that the LDLN Services are currently only available during office hours Monday-Friday, which may not accord with actual patient need. This was seen as a particular issue where there was no service cover for annual leave and cover, leading to lack of or delayed response to requests for support.

- *Awareness*: raising and maintaining awareness of the LDLN service was seen as a challenge by many, with numerous staff reporting that until they had direct involvement with the liaison nurse, they had not been aware that the service existed. General Practitioners in particular had little awareness of the service. Many acknowledged the challenge presented, given in most cases the service is a single individual covering several hospitals. One carer who has experience of the liaison service expressed exasperation at the fact that many staff did not appear to know about it.

  > *The amount of staff who don't know, they don't know who you're talking about, don't know her contact number, and you're like 'she trains in this hospital, how can you not know?' and oh, at times it was like hitting your head off a brick wall and I would end up and going using my mobile to phone [Liaison Nurse] to tell [her] 'look, we're in'. It's just they don't have any knowledge of her. I find that really, really strange. [Carer 9]*

- *Resource*: many stakeholders felt that the existing staffing resource was inadequate, leading to the service being *'stretched fairly thin at times'* [Hospital Nurse]. For the liaison nurses the logistics of covering several hospital sites was a challenge and the situation was exacerbated in services where there was only one postholder.

4.8 Outcomes influenced by the LDLN Services

Nurses, doctors, physiotherapists, 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 Adults with Incapacity legislation.

> *Perhaps before I might [have gone] straight to the Adults with Incapacity certification but 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… [Clinical Nurse Specialist]*

> *So he's made a decision that he is interested in the quality of his life which revolves around drugs, rather than the quantity of his life. And so [Liaison Nurse] has facilitated assessment of that. [Hospital Consultant]*

One doctor went as far as to suggest that the liaison nurse had been instrumental in preventing a potentially avoidable death.

> *I think that patient would very likely not be alive anymore, the dialysis patient would not be alive anymore if [Liaison Nurse 2] hadn't had input into his management [Hospital Consultant].*

For the liaison nurses their main criteria for a positive outcome were that a patient and carer had a constructive experience and viewed their next hospital attendance as positive.

> *For me the greatest satisfaction is just somebody thanking you and from their perspective whatever's happened has been made easier, and to me, that's stuff you can't quantify. [Liaison Nurse 4].*

Simply facilitating a successful hospital journey on the same lines as any other patient was seen as an important outcome.

> *I think most of my successful outcomes have come through the fact that I can get a child or an adult who previously have had difficulty accessing the service, you can get them in, you can provide the same standard of care, the procedure can be done and they can be discharged, and you're part of that whole multi-professional input to allow that to happen. And to me that's a successful outcome for Liaison Services [Liaison Nurse 5]*

4.8.1 'Taking the Pressure Off'

A recurring theme in terms of outcomes was the sense of the liaison nurses 'taking the pressure off'. For patients and carers this came in the form of providing reassurance particularly in terms of the hospital processes and in organising reasonable adjustments. For staff there was clear recognition of feeling supported by the liaison nurses in situations that may at times be challenging and stressful.

> *I don't think people expect us to make everything marvellous and change the whole system, but if there's just somebody there that can maybe make a difference for them. [Liaison Nurse 2].*

The liaison nurses' contribution was often to act as trouble shooter or mediator and was seen to lead to an improvement in relationships, in some cases between general hospital staff and carers, and in others between general hospital and learning disability services.

> *Oh very much, yeah. I mean, it's – it is that fine line where the relatives perceive the nurses as not doing their job, and we perceive them as being overly intense, and there's that balance where [Liaison Nurse 1] or [Liaison Nurse 4] can see that, yeah, I know that you need to do, the nursing staff need to do this, but the carers are also just looking out for their own. And it's that middle ground that maybe sometimes we need to be balanced, a wee bit more balanced, a wee bit more perspective, and they can bring that bit more perspective to our work [Nurse – General Medical Ward].*

Staff and patients both reported an increase in their own sense of confidence as a direct result of the intervention of the liaison nurse.

> *So it does sort of breakdown a few barriers if someone is a bit worried about you know. I've got a member of staff who's anxious about caring for someone with a learning disability, but [Liaison Nurse] will say 'just handle it this way and do this with this patient and things will be fine'. And you know, he's always there to sort of offer advice. [Charge Nurse – Day Admissions Unit].*

5. DISCUSSION

5.1 Conceptual Model of the LDLN Services

Data from both the quantitative and qualitative elements of the study have led to the generation of a conceptual model (Figure 2 overleaf) 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.

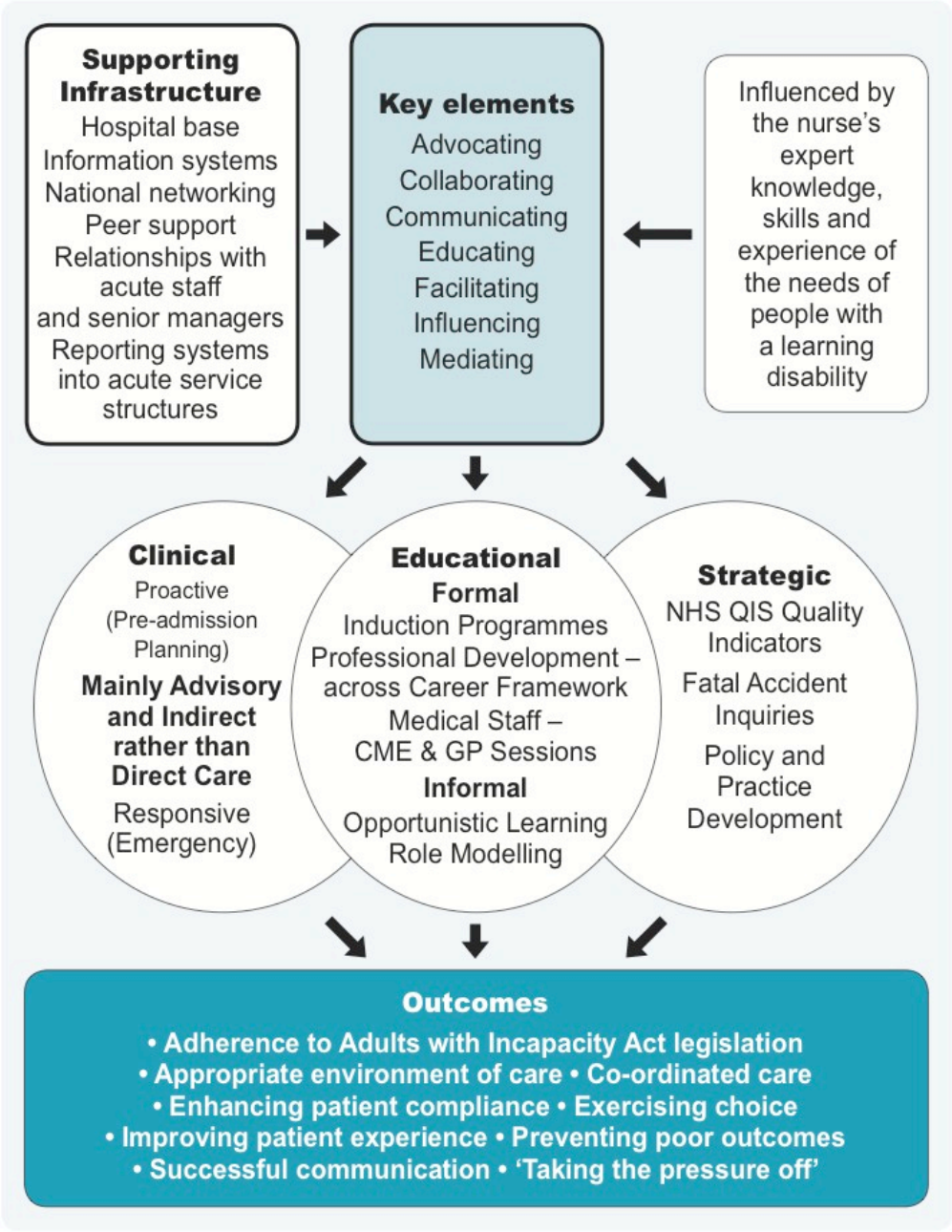


Figure 2 – Conceptual Model of Learning Disability Liaison Nursing Service

From the data it has been possible to illustrate exemplars of the key elements of the role as different stakeholders described them. This information, along with the ingredients for success outlined in Section 6.3 serve usefully to develop future service plans, job profiles and person specifications.

Advocate	• Being a credible ambassador for people with a learning disability. • Fostering equal care through recommending reasonable and achievable adjustments and, where needed, representing the views of patients and carers to general hospital staff. • Ensuring recognition of and adherence to specific legislation such as Adults with Incapacity Act, Disability Discrimination Act and sensitive policies such as 'do not resuscitate' orders.
Collaborate	• Being seen as the lynchpin between services, sectors and individuals.
Communicate	• Ensuring information flow across healthcare environments, professional groups and between health staff and carers. • Advising general hospital staff on specific communication issues and methods to enhance and ensure understanding (including advising on augmented communication and the provision of specialist resources).
Educate	• Formally through induction, updates, CPD programmes and skill development. • Informally, particularly through opportunistic learning opportunities and role modelling. • Educating different professional groups, with particular need for input with medical staff.
Mediate	• Building bridges between services (across agencies, health boards) • Speaking the same language as both learning disability and general hospital professionals. • Removing barriers.
Facilitate	• Supporting reasonable and achievable adjustments. • Enabling access to care through arrangement and adjustment of appointments, pre-hospital preparation, accessible information. • Ensuring the provision of appropriate environments of care.

Table 7: Key Elements of the Learning Disability Liaison Nurse Role

5.2 Outcomes

It is evident from the data that different stakeholders placed different priority on the achievement of outcomes, summarised in Table 8 overleaf. All, however, placed an emphasis on co-ordinated care. It is important, therefore, that a range of measures is judged when examining the outcomes of such services, with recognition that the potential contribution of LDLNs to individuals, teams and the organisation as a whole should be considered. Given the evidence on poor patient and carer experience previously cited, it is particularly vital that priority is given to these types of outcome measures.

Stakeholder	Element of Role	Outcome
All	Communication Networking Negotiation	Co-ordinated care
Patients and Carers	Expertise and support (particularly communication and behavioural)	Reasonable adjustments to care Facilitating access
Patients and Carers	Advocacy Enabling communication needs	Patient choice Patient experience
Professionals	Preadmission planning Organising reasonable adjustments	Taking the pressure off Successful investigations and treatment
Professionals	Role modelling	Increased confidence
Professionals	Information and advice	Adherence to incapacity legislation
Health Boards	Knowledge and Skills – 'credible ambassadors'	Contribution to mainstream and specialist policy development

Table 8: Stakeholder Perspectives on Outcomes

5.3 Ingredients for success

From the data it has been possible to identify a number of factors that would seem to be pertinent and influential on the success of the LDLN Services. These are illustrated in Table 9 overleaf and should be seen as being relevant for planning purposes, either in the establishment of new services or in the review of an existing one.

The importance of relationships was repeatedly emphasized by all stakeholders.

> *Yes, but it's a two-way thing, and because we know [Liaison Nurse] and we know the crew now that work in learning disabilities, it tends to be quite a smooth path. It's [first names] and [first name] and [first name], it's, you know, we know each other, so that works quite well. And I think because we're a challenging service, in terms of what we're actually doing to patients, it's not a, I don't know, an eye test, it's a big operation, they've got quite familiar with our processes, they know what to expect now and that works quite well, that relationship [Cardiology Nurse Specialist].*

Factor	Ingredient for Success	Rationale
Characteristics of the Liaison Nurses	Credible Ambassador • Extensive knowledge and skills about learning disability • Confidence and Assertiveness • Diplomatic and negotiating skills	Important for inclusion in person specification and evidencing at interview
Location of Liaison Nurse	• Hospital base with access to local information systems • Visibility – 'walking the walk'	• Efficiency of access to information • Maintenance of awareness of service • Opportunistic contact
Learning Disability (LD) Networks	• Strong local LD clinical networks – Speech & Language Therapy, Psychiatry, Clinical Psychology etc • Integration into local LD management systems • National Learning Disability Liaison Network • Learning Disability Managed Care Networks	• Enhancement of clinical practice for individual patients • CPD opportunities, supervision and support • Sharing best practice, development integrated systems, peer support • Advice on clinical effectiveness, raising profile liaison service, strategic involvement
Relationships	• Utilising existing relationships (specialist, learning disability services, support services, learning disability organisations) • With senior nursing personnel within general hospital settings • Building relationships with key individuals in general hospitals (e.g. specialist nurses, discharge co-ordinators, waiting list managers, appointments staff)	• Enhances co-ordination of complex care pathways • Integration into strategic planning • Direct involvement in problem-solving • Raising and maintaining awareness of core issues • Addressing resource issues relating to individual patient need. • Ability to address and influence key elements of patient's journey through hospital system.
Partnership Working in Area of High Need	• Identifying areas of high need – e.g. accident and emergency, respiratory units, acute receiving area, clinical neurosciences, gastroenterology, surgical receiving areas	• Prioritise liaison nursing resource to obtain maximum impact

Table 9: Ingredients for Success in Developing Learning Disability Liaison Services

6. RECOMMENDATIONS

There are three overarching recommendations from the study, along with a number of specific service developments that should be considered.

6.1 General Recommendations

1. LDLN services should be developed in areas where they do not already exist.
2. LDLN 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.

6.2 Service Developments

Whilst there was overall satisfaction with the liaison services in each of the Health Board areas there were a number of key recommendations for future service developments.

6.2.1 Alert Systems

The liaison nurses were particularly keen to explore the **potential of alert systems linked to electronic patient management systems**. They anticipated that alerts would prompt hospital staff to make contact with a liaison nurse, carer, or member of the community learning disability team prior to attendance, to find out whether the patient had specific or additional needs that warranted a reasonable adjustment. They also were keen to see a link between the Quality and Outcomes Framework(QOF) register of Adults with Learning Disability held by GPs and the patient information systems in the hospitals, so that if an individual with a learning disability presented as an emergency or through unscheduled care services their details would be accessible. However, they did recognise that there were a number of governance issues to be addressed surrounding consent and data protection, along with ethical concerns about individuals being labelled. Interfaces between systems were also seen as an issue and a barrier to progress.

6.2.2 Resource

There were calls from each stakeholder group for **an increase in the liaison nursing resource in order to provide out of hours and weekend cover**. Some felt that it was necessary for there to be one nurse per hospital in order to avoid many of the geographical challenges currently presented. An increase in resource was also seen as important to ensure that children's services were also covered, as this is not currently the case in two of the NHS Boards.

6.2.3 Development Plan

The liaison nurses recognised that the individual services had undergone an organic development process, and that there was now a need for a **formal development plan across the South East Scotland Learning Disability Managed Care Network**. Timing was felt to be right given the recent NHS Quality Improvement Scotland service reviews and the publication of the report, *Tackling Indifference* (NHS Quality Improvement Scotland 2009). This would also permit greater proactivity with developing resources such as care pathways rather than delivering a largely reactive service. It would also lead to improved consistency of working practices between the different liaison services as the patient care journey can necessitate referral to specialist centres in other NHS Board areas.

6.2.4 Promotion of the Service

There were strong calls for **improved promotion of the service particularly within primary care and to GPs** as a means to enable pre attendance planning prior to admission.

6.2.5 Permanent Funding

Historically most liaison services are established with short term funding, often as a local pilot, which creates uncertainty for the post holder and inhibits longer term planning and development. Given the emerging evidence on impact there is a need for a **commitment to permanent funding in all NHS Boards**.

6.2.6 Skill Mix

One of the liaison nurses saw the **potential for the creation of a LDLN team in each Board** with perhaps a lead nurse, staff nurse and possibly a healthcare support worker. This would support greater balance between the strategic, educational and direct elements of the role.

7. LIMITATIONS OF THE STUDY

Whilst the researchers believe the study answered the questions that it set out to, there are a number of limitations. The four services are all at different points in their development: the NHS Lothian service has been established for 10 years whilst Forth Valley has more recently appointed a liaison nurse. Partially linked to the differing lengths of time since establishment, the services were at different stages of evolution and thus not directly comparable. However, there was useful information in terms of comparing different models of service delivery.

The study included limited numbers of service users and carers, with a bias towards healthcare professionals. There is also the possibility that liaison nurses, who were relied upon to recruit participants, were biased in their selection of candidates, possibly favouring cases with a more positive outcome.

The study was conducted during the period when the NHS Quality Improvement Scotland (QIS) review of general health services across all Scottish NHS Boards was being conducted and this may have raised the profile of the liaison nurses above the level that may have otherwise been expected. Additionally, the QIS review caused an increased administrative burden upon the liaison nurses themselves, thus possibly affecting the numbers of patients seen for a period of approximately 2 months during the study. Finally, and perhaps most importantly, it was not possible to identify and therefore collect data on people with a learning disability, admitted to hospital, who were not seen by the learning disability liaison nurses. This group could have provided a control group, allowing further analysis and conclusions to be drawn.

8. CONCLUSIONS

This is the first research study that has focused on the impact and outcomes of Learning Disability Liaison Services. It is a significant step forward in beginning to provide evidence-based solutions to the issue of inadequate hospital care highlighted in recent reports. The findings are important for service providers, commissioners and planners seeking to respond to the policies that demand improvement in general hospital care provided to people with a learning disability.

The LDLN services in this study were highly valued by all stakeholders through their contributing to achieving person centred outcomes. The liaison nurses have an important role in raising the profile and status of people with a learning disability in general hospitals. Their expert knowledge and skills impact on the development of effective systems and processes and to 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 organisational strategic developments within the resource allocated to each service. The results from this study highlight the challenges in delivering the complex elements of the role and the importance of the ongoing development, promotion and awareness of the LDLN service.

9. IMPORTANCE TO NHS AND POSSIBLE IMPLEMENTATION

This study is the first to be undertaken in the world that focuses on identifying the impact of learning disability liaison nurses in contributing to ensuring effective outcomes for people with a learning disability attending for general hospital care. The findings are therefore relevant to the NHS in Scotland and across the United Kingdom as well as internationally, where people with a learning disability experience similar issues relating to poor care and outcomes. The findings

from this study are particularly relevant when set within the context of a population with high and complex health needs that is growing in number and ageing. In addition there have been a number of investigations that have highlighted service and system failures that have contributed to premature and avoidable deaths.

The mixed methods research design that was employed allowed for the identification of the range and scope of the liaison nursing activity across four NHS Boards and the elements of the services that are most effective in bringing about person-centred outcomes. The findings are supported by the experiences of key stakeholders, including people with learning disabilities and their carers. There is, therefore, scope to develop liaison nursing services across the NHS that contribute to ensuring quality care and a positive patient experience. The Conceptual Model of a learning disability liaison nursing service highlights the complex nature of the role and the interplay between the elements of the service that impact on care outcomes and the effective use of the liaison nursing resource.

There is also potential for exploring the application of this model (i.e. the provision of specialist expertise to support access and reasonable adjustments) for other vulnerable groups who are known to be at particular risk in general hospital settings, or where there is evidence of poorer care outcomes. This might include people with dementia.

The evidence arising from this study presents the opportunity to ensure that new models of care are developed for the future by recognising the unique contribution that the knowledge and skills of the learning disability liaison nurses bring strategically, and educationally to the organisation and most importantly to the individual patient and carer experience.

10. FUTURE RESEARCH

This study has already gone a long way towards improving the knowledge base surrounding the ways in which LDLN services function, and how these services are viewed and valued. The study has pointed to a number of areas that would merit future investigation, including the use of the Adults with Incapacity Act (Scotland) 2000 and the economic impact of liaison services. There is also the potential to examine the impact of specific approaches to reasonable adjustment, including the use of particular techniques for augmented communication within general hospital settings.

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