

Learning Disability Liaison Project summary

Understanding the who, where and what of Learning Disability Liaison Nurses

Introduction

This project was set up to:

- Help the NHS understand who Learning Disability Liaison nurses are and where they work
- Help the NHS in the work they are doing across the country to recruit more nurses and encourage nurses not to leave
- Find out what is needed to help liaison nurses in their work to stop people dying before they should and improve NHS treatment for people with learning disabilities.

Local differences

The review showed us that liaison services depend on where you live.

- In some areas there are teams of liaison nurses able to provide a good service to people with learning disabilities and their families.
- In some areas there are no liaison nurses working with GPs or in hospitals.
- In others, one nurse is working with several GP Practices or hospitals
- Some nurses work part-time.

When nurses leave, it can take a long time to find a new one, or in some cases the job is cut. When this happens, families and self-advocates told us about lots of difficulties in accessing help and support.

Nurses told us some Trusts are very welcoming and keen to have liaison nurses and others aren't.

Most of the nurses who took part in the project worked in hospitals or with GP practices. A small number of liaison nurses working in different settings like mental health, autism and intensive support also took part.

Some organisations have good plans to improve the health of people with learning disabilities and they make good reasonable adjustments, but several people told us about problems and poor attitudes in some Trusts. Families told us about difficulties with health staff listening to them when no learning disability nurse is available to help.

Survey

We did a survey to find out what nurses think about their jobs. The survey was about the nurses' experience working in a learning disability liaison role. It told us about the support nurses offer to people who have learning disabilities and their families, what they do and how they help to keep people safe, listened to and understood to ensure good health.

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Job Descriptions

We found the nurses' job descriptions were different. All of them included key responsibilities linked to support, most included care, carers and or families and training or education and research. Some key words were expected to be seen but only featured in a few e.g. communication, easy read, access, facilitation, liaison, reasonable adjustments. Some nurses were based in acute hospitals, some in community teams, one in a mental health hospital and some in primary care.

Focus groups and interviews

Self-advocates

The self-advocates had mixed experiences:

- Some self-advocates reported good experiences with a liaison nurse.
- Some people had difficulty in connecting with an acute liaison nurse at the hospital. This gave rise to confusion, worry and fears.
- Others talked about the need for help and support when they were at the hospital with their sick relatives.
- Several of the self-advocates were worried about DNACPR. They were concerned if they were admitted to hospital they would not be resuscitated.

The self-advocates agreed there are not enough liaison nurses, saying more learning disability liaison nurses should be trained. The self-advocates want liaison nurses to help health staff do things differently.

Families

In general, the families who had experienced support from a liaison nurse were positive about their role. However, their main concern was the low number of liaison nurses and the inconsistency in liaison nursing with some areas well served and other areas with no nurses at all. Some families expressed concerns that there is a variation in the quality and expertise of liaison nurses with some doing an outstanding job and others less so.

There was strong support from families for the importance and value of the role and how it can make a significant difference. They were concerned that a lot of people don't know there are liaison nurses or anything about what they do.

Liaison nurses

The nurses reflected the findings from the survey in their responses. The overwhelming message related to the small number of nurses and their limited capacity to do everything needed. Some nurses expressed difficulties in being recognised as useful within the organisation, whilst others felt they were valued by colleagues and able to act independently.

Building working relationships and developing good links with individuals and departments was seen as an essential component of the role, enabling and encouraging reasonable adjustments. A lot of nurses told us how important it is for them to understand the importance of the law and national guidelines. They said an important job they have is to be an advocate for people in relation to these.

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A conflicting issue was the impact of safeguarding. For some, being placed within the safeguarding team was a positive experience presenting opportunities for support. For others, the opposite was true with them being pulled away from their specialist role to focus on wider safeguarding issues. There were similar conflicts identified by nurses employed by one Trust and hosted by another. For some, the pressures of expectation from each organisation made effective working difficult. Several nurses held joint roles e.g. working in both primary and acute care.

A lot of nurses work as the only learning disability nurse in an organisation. This raised concerns about visibility, isolation, support, supervision, and professional development. Some nurses expressed a feeling of not really belonging to any team.

Most nurses were employed at band 6. Within their roles they felt a responsibility to work both strategically and at grass roots. This put huge demands on their time and capacity to be effective, with the need for constant prioritisation and at times resulting in them not being able to see people with learning disabilities during an admission

All liaison nurses spend a proportion of time on staff training, raising awareness about learning disability and autism, capacity, consent, reasonable adjustments, and accessible communication. Most nurses had not had extra training in how to teach and train others. At times they also act as role models, demonstrating effective approaches to enable therapeutic interventions and challenging diagnostic overshadowing and negative or discriminatory attitudes.

Liaison nurses work closely with families and carers, this represents a large part of the role. Several nurses told us training for acute liaison nurses needs to include orientation in the acute hospital and practical experience placements which include ward and department placements, shadowing, and engagement with clinical staff. The most relevant would be in respiratory medicine, neurology, orthopaedics, A&E, out-patients, Pre-op assessment, post op recovery, bed management and discharge liaison.

The nurses suggested there is a need to raise the profile of the role to fulfil a fundamental basic need for people with learning disabilities and people with autism. Liaison nurse roles look like more traditional nurse roles. Developing the role and an associated career pathway, might help with recruitment and traction, movement around profile, and the reduction of premature death.

Conclusion

A major issue identified by this project was the small number of learning disability liaison nurses and the limitations this can put on the effectiveness of the role which can be very isolating for nurses working alone. There are limited opportunities for career progression in liaison nursing. The role appears most effective in Trusts where there are teams of liaison nurses providing a grass roots to strategic approach.

Liaison nurses are valued by self-advocates and families, but some inconsistency exists in the skills and experience of nurses. A lot of self-advocates and families don't know about liaison nurses or how to get their help.

Most liaison nurses have not undertaken any additional training specific to the role, relying on previous experience, learning on the job and by trial and error.

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Recommendations

Recommendation 1: Develop a clear career pathway enabling nurses to progress clinically and professionally within liaison settings.

Recommendation 2: Develop a nationally recognised 'liaison nurse' competency framework, identifying competencies at different stages of the role.

Recommendation 3: Review the title 'liaison nurse' to change the emphasis to the actual role of the nurse and fit in with titles used and recognised in the healthcare setting where the nurses work.

Recommendation 4: Explore the creation of a commissioning strategy to enable further development of Acute Liaison teams and Primary Care health facilitation teams. These teams should have a clear remit to support the reduction of premature deaths, support access to effective treatment, and improve the health and wellbeing of people who have learning disabilities across the lifespan.

This summary was produced by Health Education England with Learning Disability England, In Control and Gwen Moulster Consultancy.

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