

In this article...

- Need for improved care of people with learning disabilities admitted to hospital
- Role and responsibilities of learning disability champions in an acute trust
- Benefits and challenges of setting up a network of learning disability champions

Introducing learning disability champions in an acute hospital

Key points

Addressing the needs of hospital inpatients with learning disabilities is a top priority

There is still a lack of learning disability liaison nurses in acute settings

Learning disability champions can act as a link between liaison nurses and hospital wards

The champions can be a source of support and knowledge for both staff and patients

Royal Liverpool and Broadgreen University Hospitals Trust has a network of 110 learning disability champions

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Abstract Although there have been recent improvements, a lot more needs to be done to achieve equitable care for people with learning disabilities admitted to hospital. The increasing number of acute learning disability nurses can have a positive effect but these nurses cannot do everything. At Royal Liverpool and Broadgreen University Hospitals Trust, two liaison nurses have recruited a large and growing network of learning disability champions, who act as a resource on the wards for both patients and staff. This article describes the project and its achievements so far.

Citation Jennings G (2019) Introducing learning disability champions in an acute hospital. *Nursing Times* [online]; 115: 4, 44-47.

Increasing numbers of acute trusts employ liaison learning disability nurses in an attempt to improve the care provided to people with learning disabilities who are admitted to hospital. However, improving that care requires engagement and support from all staff, not just liaison nurses. Learning disability champions can help in that respect as they provide a link between the acute liaison team and the wards. This article describes the learning disability champions network created in 2017 at Royal Liverpool and Broadgreen University Hospitals Trust (RLBUHT) – to date, it has 110 champions acting as a source of support and knowledge for patients, relatives and staff alike.

Health inequalities

People with learning disabilities receive poorer hospital care than the general population (Heslop et al, 2013; Mencap, 2012; Michael, 2008; Mencap, 2007) and the Learning Disabilities Mortality Review Programme (2018) found that the proportion of people with learning disabilities who died in hospital was far greater than

the proportion of hospital deaths in the general population (64% versus 47%). Although there are areas of good practice, equitable healthcare for people with learning disabilities in hospital has still not been achieved.

There is a range of factors influencing how people with learning disabilities are cared for in NHS hospitals, including:

- Staff attitudes towards them;
- Whether they have an informal carer to support them;
- To what extent staff involve their informal carers;
- How well staff communicate between themselves, as well as wider environmental and organisational factors (Backer et al, 2009).

More than 10 years ago, it was recommended that all acute healthcare settings in the UK should have learning disability liaison nurses (Michael, 2008). However, six years later, in 2013, the report of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities found that there was still a lack of acute liaison nurses (Heslop et al, 2013), while a growing body of literature reported

negative experiences of people with learning disabilities in hospital.

Today, the provision of liaison nurses in acute hospital settings remains patchy and acute care is still an area in which people with learning disabilities face inequalities that potentially lead to avoidable deaths. The NHS has stepped up its efforts to address this: in 2018, it published learning disability improvement standards for NHS trusts (Bit.ly/NHSILearningDisabilityStandards) and involved people with learning disabilities (NHS, 2018) in its consultation of users about its long-term plan (longtermplan.nhs.uk).

“The champions’ network has provided a vehicle to promote the learning disability agenda”

Our learning disability liaison service

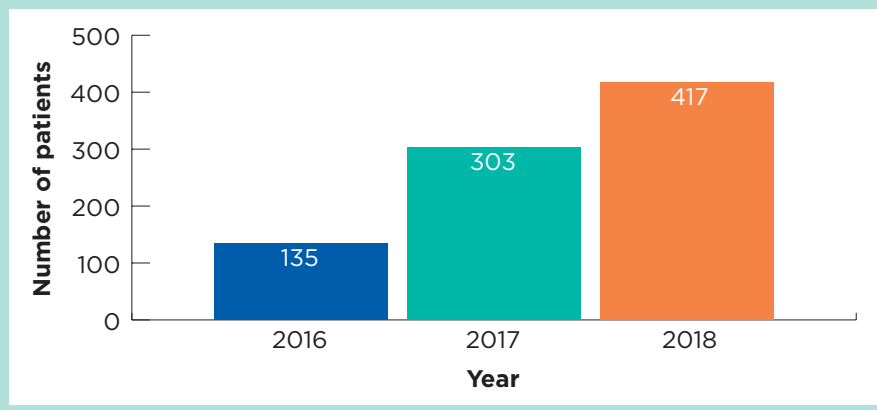
In Merseyside, only two acute trusts out of nine – RLBUHT and Alder Hey Children’s Foundation Trust – have an acute learning disability liaison team. The liaison team at RLBUHT was created in 2016 and has two nurses (Serena Jones and I), who work as part of the safeguarding team. The number of patients supported by the liaison team has continually grown since its creation, with an increase of almost 40% between 2017 and 2018 (Fig 1). However, an acute liaison team is not sufficient to bring about cultural change: the commitment of staff in clinical areas is needed.

To promote staff engagement across the trust and improve care for patients with learning disabilities, we decided, as part of the trust’s 2017 plan for the liaison team, to set up a network of learning disability champions. There are differing views about the usefulness of champions or link nurses in the hospital setting. Legg et al (2017) surmise that the role is beneficial, as it makes direct support available to patients at all times. However, anonymous readers commenting on a blog about link nurses by Shepherd (2013) argued that, in an under-resourced NHS, if no extra time or resources are allocated to undertake the role properly, it can become a tick-box exercise and not make much difference.

Recruiting champions

Our learning disability champions act as a link between the learning disability team and staff/patients in the clinical areas. For the role to work well, it needs to be autonomous, with the champion free to make

Fig 1. Patients supported by the learning disability liaison team



decisions independently of the ward management. Champions need to be committed and passionate about supporting patients and communicating with the wider team. We opted for the name ‘champion’, rather than ‘link nurse’, to highlight that the role is open to all staff, not just certain pay bands or roles.

We recruit champions:

- Through our training events;
- Via our webpage (Bit.ly/RLbLD);
- Via the internal communications department.

Some staff approach us unprompted to express their interest in being a champion. Currently, there are 110 learning disability champions at the trust. They include:

- Nurses;
- Healthcare assistants;
- Therapists;
- Students;
- The CEO of the trust;
- The director of nursing;
- Medical staff;
- Trust volunteers with learning disabilities and/or autism;
- Volunteers’ relatives.

For us, having the support of trust volunteers and their relatives was invaluable.

Training champions

Champions sign a contract to formalise their commitment, which details their role and responsibilities. They are trained to foundation level in learning disability and autism awareness. The training is provided face-to-face and participants receive a certificate of attainment. The training session, which lasts an hour, focuses on:

- Health inequities in acute hospitals;
- How clinical staff can improve the care they provide.

Beyond this basic training, we also organise specialist training sessions to further enhance champions’ knowledge,

though this is limited by time and resource constraints.

Becoming a champion is an opportunity for staff to develop and demonstrate leadership – which, in the case of nurses, is a requirement of the Nursing and Midwifery Council’s (2018) code. Champions receive a certificate they can save in their personal portfolio as evidence of the additional work undertaken. They also receive a metal pin badge, which makes it easier for patients to identify them. Finally, an annual awards ceremony recognises their commitment and achievements.

What champions do

The role of champions is to:

- Advocate for vulnerable patients and their families;
- Be a source of information and support in their clinical area;
- Disseminate information from the liaison team in the clinical areas.

In this way, they help to continuously improve patient care and ensure that addressing the needs of patients with learning disabilities remains a top priority. We ask champions to create a one-page profile about themselves and set up a learning disability noticeboard in their ward or clinical area. We also invite them to attend quarterly meetings.

We aim to have two champions per ward but this is not limited – some wards have three.

One-page profiles

I wanted to humanise the care we provide and thought one-page profiles (Bit.ly/SCIEOnePage, Bit.ly/SandersonOnePage) would be a good way of doing this. The original idea of one-page profiles was that they are created by people with learning disabilities and/or autism to explain who they are, what matters to them, how they

Fig 2. A ward learning disabilities noticeboard



want to be supported and whether they need reasonable adjustments. Health and social care professionals can use the profiles to find out, at a glance, what support needs service users have.

I adapted the idea and, in our case, it is the champions who create their profiles for the benefit of patients, relatives and carers. The profiles are a way of introducing champions to patients, so patients feel more acquainted and at ease with the champion(s) on their ward.

Champions are encouraged to be creative when designing their profiles, which can take two forms:

- Rich in text and more corporate in style;
- More colourful and easier to read, with emojis, pictures and a small amount of text.

According to patient feedback, people with autism generally prefer the text-rich format while those with learning disabilities favour the easy-read version.

Introducing the idea of one-page profiles was challenging. Some champions questioned their validity and needed an explanation. On a technical level, there can

be formatting issues. At the time of writing, 43 of our 110 champions have completed their profile. These profiles:

- Are included in the learning disability information pack that is given to patients and families on admission;
- Feature on ward noticeboards (where these exist).

Ward noticeboards

Patients with learning disabilities and/or autism need to know how to contact the learning disability liaison team if a

problem arises. Champions are therefore asked to set up, in their clinical area, a noticeboard that must contain the liaison team's contact details. The noticeboards also feature the ward champions' profiles and a blank health passport as an example.

As with their one-page profile, champions are encouraged to be creative when designing the noticeboard and add any content they think is helpful – for example, Makaton symbols (www.makaton.org). Currently, of the 55 ward areas, 24 have a learning disability noticeboard; Fig 2 shows one of them.

Quarterly meetings

Quarterly meetings are held to disseminate information and fuel champions' commitment. People with learning disabilities and/or autism are regularly invited to speak at these meetings, to explain how it feels to be a patient in an acute hospital. Meetings are also an opportunity for champions to share best practice, give each other peer support and discuss service innovations that could be replicated.

Outcomes and feedback

Our learning disability champions have helped improve the experience of hospital care for people with learning disabilities; Box 1 features a case study illustrating this. They may also have helped reduce lengths of stay in hospital. Fig 3 shows the average length of stay of patients with learning disabilities at our trust in the past three years: it has fallen from 18 days in the second half of 2016 to 8.9 days in 2018. Numerous factors could have contributed to this reduction, but it has coincided with the creation of the champions' network.

The learning disability team undertakes a post-discharge telephone survey, which is offered to all patients and their family/carers, fitting in with the 'ask, listen, do' agenda (NHS, 2018). Although the three questions asked do not relate to the champions, five respondents specifically stated

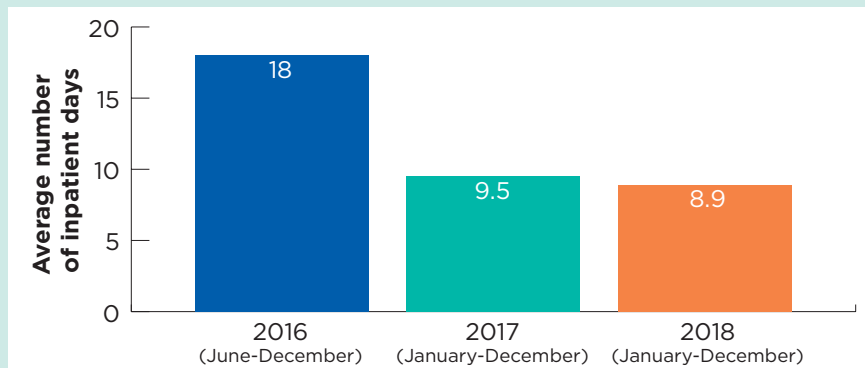
Box 1. Case study

Jack Taylor* is a young man with profound, multiple learning disabilities and autism. He also has epilepsy. He has been known to the learning disability liaison team for a number of years and, when he comes to hospital, is always supported by his parents. On a recent admission, a ward champion made reasonable adjustments to improve his stay. The champion successfully made the case for Mr Taylor to have a private room with an extra bed for his mother so she could sleep next to him. This reduced his anxiety and improved the monitoring of his epileptic seizures. In the post-discharge telephone call, Mr Taylor's mother said: "Nurses were lovely. Can't praise them enough. Provided us a side room."

*The patient's name has been changed

Clinical Practice Innovation

Fig 3. Length of stay of patients with learning disabilities and/or autism at RLBUHT



RLBUHT = Royal Liverpool and Broadgreen University Hospitals Trust

that the ward-based care had been excellent and cited 'link staff' and 'champions' in their appraisal without prompting.

The learning disability champions themselves have provided information, via a postal questionnaire, on why they have taken on the role. Box 2 features some of their comments.

Next steps

The trust's learning disability champions' network at RLBUHT has grown rapidly. Although time-consuming and labour-intensive for the liaison team, setting up the network has resulted in positive outcomes for all involved. It has provided a

vehicle to promote the learning disability agenda across the trust, increased staff engagement and awareness, and improved practice, notably through a better understanding of reasonable adjustments.

In 2019, our plans for the champions network are to:

- Ensure all champions have a one-page profile;
- Ensure >80% of clinical areas have a learning disability noticeboard;
- Expand the role of champions to include training other members of staff, the ultimate aim being that all staff receive foundation-level training in learning disability and

autism awareness;

- Create a social media group to offer alternative ways of disseminating information and ideas;
- Collaborate with Alder Hey Children's Foundation Trust to grow the network regionally.

Conclusion

Achieving equity of hospital care between patients with learning disabilities and the general population must remain a priority. Current projections indicate that patient numbers will continue to rise in 2019 and beyond – this means that a growing number of patients with learning disabilities will need the support of the acute liaison team and, beyond that, of all clinical staff. The engagement of staff will be essential to provide optimal care for patients. Having more champions will be key to increasing staff members' awareness and knowledge of the complex health needs of people with learning disabilities and, ultimately, to stop them dying of avoidable causes while in hospital. **NT**

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Box 2. Champions' comments: why they took on the role

"People with vulnerabilities do sometimes require a little more or a lot more support when in hospital [...] It is important they have the support and adjustments made to enable them to make informed choices themselves."

"It is important not only because I am a ward manager and I want the care of all patients on my ward to be appropriate and reasonably adjusted, but also because it is very close to my heart, as I have a family member with autism."

"Last year we had a patient who had autism, he was quite unwell [...] I felt, as a ward, we didn't do enough for him while he was with us. I believe witnessing this patient's [...] low mood made me realise how much more we could do."

"Being a learning disability champion keeps my overall knowledge of learning disabilities up to date. This assists me when working with our volunteers who have a learning disability. It gives me an insight and understanding of their situation."

"I know how frightening it can be as a patient in hospital – worried about what will happen, what treatment you will need, and being away from your home and family. [...] All these thoughts and feelings are magnified if you have a learning disability."

"I want to be a learning disability champion because I am [...] a parent and carer of someone with autism and [a] learning disability, as well as a member of staff. I will do all I can to ensure all patients accessing our hospital services have an inclusive experience tailored to their needs."



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- A 'VIP pathway' for vulnerable people receiving elective surgery
[Bit.ly/NTVIPPathway](http://bit.ly/NTVIPPathway)