

# Formative Review of the Care of People with Learning Disabilities

## Shropshire and Telford & Wrekin Health Economy

Visit Date: 9<sup>th</sup> November 2016

Report Date: February 2017

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## INTRODUCTION

This report presents the findings of the formative review of the care of people with learning disability prior to, during and after admission to acute hospital care in Shropshire, Telford & Wrekin. This review took place on 9<sup>th</sup> November 2016 and used the following framework of questions:

Formative Review Questions	
<b>Prior to admission:</b>	
1.	What is precipitating admission to hospital? Could admissions to hospital be avoided?
<b>On admission:</b>	
2.	Are people with learning disabilities 'flagged' to hospital staff as potentially vulnerable by primary care and their specialist services MDT?
3.	Are ward staff aware of any health or communication passports the person brings with them and are these used by ward staff?
4.	How are other professionals involved in a person's care informed of their admission to hospital?
5.	How is important information about communication and care shared with, and acted on by, the ward team?
6.	Is capacity assessed? Where capacity is not present, what best interest approaches are used and who is involved in this?
7.	Are reasonable adjustments identified and implemented in care and treatment?
<b>During admission:</b>	
8.	What arrangements are in place to ensure safe and effective care and treatment of people with learning disability while in hospital? What approaches do hospitals use if they do not have an acute liaison nurse for people with learning disabilities?
9.	Are families/carers supported, involved, able to give advice and knowledge of the best way to care and communicate with the person with learning disabilities?
10.	Do learning disability services liaise with hospital teams during admissions of people with learning disabilities and vice versa?
11.	How are people with learning disabilities involved in developing their care plans? How are advocates, families and care providers involved in the process of developing care plans?
12.	Are joint care plans developed between the hospital and specialist learning disability services/care providers?
<b>Preparation for discharge</b>	
13.	How is discharge planning coordinated? How are the person with learning disabilities, their advocates, families and care providers and learning disability specialist services involved in discharge planning?
14.	How is information on follow up care communicated to the person with learning disabilities and everyone involved in their care?
15.	What follow on care after discharge was arranged? Could post-discharge care have been improved?
16.	What processes exist to address any concerns regarding care and treatment? How well do these work?
<b>Staff training:</b>	
17.	Do staff have training in 'best interests' and Mental Capacity Act and, when asked, can they demonstrate a good understanding in relation to caring for a person with learning disabilities?
18.	Is on-going learning disability awareness training provided for all health care staff including porters, cleaners, receptionists, senior managers and administrators?

## Formative Review Questions

### Patient feedback:

19. Is there evidence of feedback from service users with learning disabilities and their carers and families?
20. Is there evidence of actions taken as a result of feedback?

The report reflects the situation at the time of the visit. Appendix 1 lists the team which reviewed the services in Shropshire and Telford & Wrekin.

During the course of the visit reviewers met service users and carers, representatives from a range of service providers, and commissioners. Reviewers visited several wards at both Princess Royal Hospital and Royal Shrewsbury Hospital. For each area of the framework reviewers asked about what was working well, whether plans were in place and what changes were needed. Some issues emerged as common themes across all parts of the framework and are described once only.

This report describes services provided or commissioned by all the NHS Trusts, Clinical Commissioning Groups (CCGs) and local authorities in Shropshire and Telford & Wrekin together with independent and voluntary sector partners. The review used a framework of questions but not a detailed review against Standards and the findings therefore do not have the same level of rigour and consistency as full peer review visit reports. Responsibility for addressing the issues identified in this report lies with all these organisations working in partnership, taking into account that this is a formative review which may not have a full picture of local services. Shropshire and Telford & Wrekin Clinical Commissioning Groups have a particular responsibility for ensuring appropriate progress is made.

## ABOUT WEST MIDLANDS QUALITY REVIEW SERVICE

WMQRS is a collaborative venture between NHS organisations in the West Midlands to help improve the quality of health services by developing evidence-based Quality Standards, carrying out developmental and supportive quality reviews (often through peer review visits), producing comparative information on the quality of services and providing development and learning for all involved.

Expected outcomes are better quality, safety and clinical outcomes, better patient and carer experience, organisations with better information about the quality of clinical services, and organisations with more confidence and competence in reviewing the quality of clinical services. More detail about the work of WMQRS is available on [www.wmqrs.nhs.uk](http://www.wmqrs.nhs.uk)

## ACKNOWLEDGMENTS

West Midlands Quality Review Service would like to thank the staff and service users and carers of Shropshire and Telford & Wrekin health and social care economies for their hard work in preparing for the review and for their kindness and helpfulness during the course of the visit. Thanks are also due to the visiting team and their employing organisations for the time and expertise they contributed to this review.

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## CARE OF PEOPLE WITH LEARNING DISABILITY PRIOR TO, DURING AND AFTER ADMISSION TO ACUTE HOSPITAL CARE

### Background

- 1 Acute hospital care was provided by The Shrewsbury and Telford Hospital NHS Trust (SaTH) at both Princess Royal Hospital, Telford and Royal Shrewsbury Hospital. Community learning disabilities services were provided by South Staffordshire and Shropshire Healthcare NHS Foundation Trust (SSSFT), including an acute liaison team and the respite service, Oak House, which was located on the Royal Shrewsbury Hospital site. The acute liaison team functioned from Monday to Friday, 9am to 5pm, and comprised two whole time equivalent members of staff. One was normally based at Princess Royal Hospital and one at Royal Shrewsbury Hospital. At the time of the review one member of the acute liaison team was on long-term sick leave and so one post was covering both hospital sites.
- 2 Reviewers noted that staff who they met had different interpretations of the purpose of the review. Reviewers have restricted themselves to the purpose and framework questions agreed before the visit and recognise that some people may therefore be disappointed in the outcome of the review.

### Summary

- 1 In general, reviewers found some examples of good practice but considerable variability in the care of people with learning disability prior to, during and after admission to acute hospital care in Shropshire and Telford & Wrekin. There was not a coordinated vision of what 'good care' looked like, and individuals' knowledge, training, enthusiasm and prioritisation of the needs of people with learning disabilities varied significantly. Some staff were very aware and keen to develop services, whereas others were less so and appeared to have little interest in this group of patients.
- 2 More senior staff were able to articulate the processes that should be followed. Ward staff at Princess Royal Hospital were generally aware of and were following expected processes. Ward staff at Royal Shrewsbury Hospital were generally less clear.
- 3 The acute liaison nurse was providing good support for people with learning disabilities admitted electively, especially those known to the community learning disabilities service. Support for those admitted as emergencies was less well organised. The system of 'flagging' people with learning disabilities admitted acutely was not robust. People with learning disabilities who were not known to the community learning disabilities service may not receive support from the acute liaison team. 'Passports' were in use, especially for people known to the community learning disabilities service.
- 4 Reviewers saw no 'easy read' information during the visit. The latest Health Communication Toolkit was not in use and reviewers suggested that this is obtained and made available on both hospital sites as a matter of urgency. The local policy was out of date, and three pathways for care of people with learning disabilities admitted to hospital were in use.
- 5 Reviewers considered that there was the potential to improve the care of people with learning disabilities admitted to acute hospitals, especially those admitted as emergencies. Reviewers suggested that local providers and commissioners work together to:
  - a. Estimate the numbers involved
  - b. Agree integrated pathways of care
  - c. Agree standards and key performance indicators for each pathway
  - d. Design services to deliver the agreed pathways
  - e. Identify the resources needed to implement the pathways, including training of all staff

- 6 Addressing these issues should result in reduced length of stay, reduction in repeat admissions, improved outcomes, improved patient experience and reduction in avoidable harm.

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Formative Review Questions	
<b>Prior to admission:</b>	
1.	<b>What is precipitating admission to hospital? Could admissions to hospital be avoided?</b>  Reviewers did not meet a GP or social work representative, and saw little evidence in relation to this question. The community learning disabilities service provided care for approximately 900 clients in Shropshire and Telford & Wrekin, and was encouraging these clients to have Health Action Plans and 'passports'. Reviewers were told that social services were aware of about twice this number of people with learning disabilities. For those not known to the community learning disabilities service, there was little evidence of health facilitation or support for developing Health Action Plans and 'passports'. Active work with primary care on improving the quality of GP registers was also not evident. This suggests that there is potential for preventing some acute hospital admissions.
<b>On admission:</b>	
2.	<b>Are people with learning disabilities 'flagged' to hospital staff as potentially vulnerable by primary care and their specialist services MDT?</b>  It was possible to 'flag' people on the Shrewsbury and Telford Hospital (SaTH) Patient Administration System (PAS). A user guide was available for how to do this, but staff training to support this was not yet in place. 'Flagging' required the hospital to be notified that the person had a learning disability, usually by their GP. There had been little recent health facilitation or other work with GPs about care of people with learning disabilities and so notification to SaTH was not routine. A lot of work had taken place on 'flagging' people with dementia, but less so for those with a learning disability, and there was also confusion about the name of the flag. The abbreviation 'ALD' appeared to be used for both 'acute liver disease' and 'adult with a learning disability'. IT systems in the Emergency Department, general community services and community learning disabilities service were fragmented, and so if a person was identified as having a learning disability this information was not then visible to other professionals accessing their own IT system. Patients who were not notified by the GP and 'flagged' could be referred to the acute liaison team by hospital staff, or the acute liaison nurses might notice them while they were on a ward.  In summary, while some people with learning disabilities were 'flagged' as potentially vulnerable, this system was not robust, especially for people admitted as emergencies.

### Formative Review Questions

**3. Are ward staff aware of any health or communication passports the person brings with them and are these used by ward staff?**

'Passports' were in place and the community learning disabilities service had recently run an initiative to ensure that all their clients had a 'passport' and knew that they should take it with them if they were admitted to hospital. Reviewers were told that clients of the community learning disabilities service would usually bring a 'passport' with them when admitted. 'Passports' were not, however, easily available during a person's hospital stay. Rather than remaining with the individual, reviewers saw several examples of 'passports' being placed in patients' medical notes or elsewhere. Medical notes, nursing notes and observations were all stored separately and the 'passport' could be kept with any of these.

Reviewers suggested that 'passports' should remain with the patient and be easily accessible to health and social care professionals. Staff at Princess Royal Hospital were generally more aware of the 'passports' than those at Royal Shrewsbury Hospital.

It was less likely that people with a learning disability who were not under the care of the community learning disabilities service would have a 'passport' and would bring this with them.

**4. How are other professionals involved in a person's care informed of their admission to hospital?**

Arrangements were in place to notify the community learning disabilities service if one of their clients was admitted to hospital, although it was not clear that these always worked as envisaged.

**5. How is important information about communication and care shared with, and acted on by, the ward team?**

See question 3. In general, communication with ward teams worked well for elective admissions when the acute liaison nurse had been involved, but was variable for emergency admissions, especially of people with learning disabilities who did not meet the criteria for the community learning disabilities service.

**6. Is capacity assessed? Where capacity is not present, what best interest approaches are used and who is involved in this?**

See question 17 in relation to staff training.

## Formative Review Questions

### 7. **Are reasonable adjustments identified and implemented in care and treatment?**

In the areas visited by reviewers, staff at Princess Royal Hospital were generally aware of the processes expected and would make reasonable adjustments.

Staff in the Emergency Department at Royal Shrewsbury Hospital were mostly aware of the processes expected, had completed the competency framework and had a resource folder. They were also aware of the acute liaison nurse. Hospital 'passports' were available and could be given to people with learning disabilities who did not have one. Some staff commented, however, that people with learning disabilities would be treated "the same as everyone else" and it was not clear that reasonable adjustments would be made in practice. There was very good information available on physical health care but no accessible information for people with learning disabilities.

On the short stay and ambulatory care units at Royal Shrewsbury Hospital staff did not have good awareness of how to respond to the needs of people with learning disabilities. Space was very limited, which made it more difficult to make reasonable adjustments. Some staff had not had Mental Capacity Act training and had not completed the learning disabilities competency handbook. Staff expected that the Emergency Department would have identified everyone with a learning disability and would have completed all the expected documentation.

Reviewers were not able to talk to registered staff on the Acute Medical Unit (AMU) due to an emergency de-brief taking place at the time of the visit.

### During admission:

### 8. **What arrangements are in place to ensure safe and effective care and treatment of people with learning disability while in hospital? What approaches do hospitals use if they do not have an acute liaison nurse for people with learning disabilities?**

Reviewers were impressed by the pleasant environment and atmosphere at Princess Royal Hospital. They commented particularly on the calm approach within the Emergency Department. They also commented on the cleanliness and pleasant smell of the hospital. Staff were aware of the acute liaison nurse.

At Royal Shrewsbury Hospital there was less awareness of the acute liaison nurse, probably because the nurse with lead responsibility for this site was on long-term sick leave and the Princess Royal Hospital nurse was covering both sites.

See question 7 in relation to the Emergency Department, short stay unit and ambulatory care unit at Royal Shrewsbury Hospital. On the AMU, staff were very caring and interacted well with one patient with a learning disability but the patient did not have a drink or call bell within reach. The patient's notes did not identify any specific needs but a note on the bed stated that she was partially blind and needed a red tray.

In general, staff at Royal Shrewsbury Hospital were less clear than those at Princess Royal Hospital about the expected policies. Staff were unsure what support was available for people with learning disabilities and who to contact. Staff could describe what they would do in a particular situation and, although this was usually reasonable, it did not always follow the process expected by more senior management.

Arrangements for communication with other departments (for example, imaging) about patients' needs were also not clear. Therapy staff were actively developing their care of people with learning disabilities, including developing therapy outcome measures.

The acute liaison team was available 9am to 5pm, Mondays to Fridays, and staff did not have access to appropriate resources or advice outside of these times.

## Formative Review Questions

9. **Are families/carers supported, involved, able to give advice and knowledge of the best way to care and communicate with the person with learning disabilities?**

At Princess Royal Hospital notice boards were well kept and clearly laid out, and included good information about support for carers.

Carers were actively involved in providing care while the person with a learning disability was in hospital, even though this was not hospital policy. It was less clear what would happen if the patient did not have a carer or if additional support was needed, especially if the patient was not a client of the community learning disabilities service.

The Carers' Strategy had a small section about carers of people with learning disability and directed carers to the acute liaison nurses. Reviewers also suggested that this strategy may benefit from review, including consideration of the 'triangle of care' approach to involving users and carers.

10. **Do learning disability services liaise with hospital teams during admissions of people with learning disabilities and vice versa?**

The acute liaison nurses would liaise with the community learning disabilities service, but see below in relation to the pressures on this team.

11. **How are people with learning disabilities involved in developing their care plans?**

Reviewers saw no 'easy read' information during their visit, including in the Patient Advice and Liaison Service (PALS) office. They also saw no guidance for staff on communication materials that were available or on how to involve people with learning disabilities. An old version of the national toolkit was available but there was no evidence that the latest Health Communication Toolkit was in use. Every Trust had been given five copies of this toolkit, which provides an excellent range of resources for use with people with learning disabilities.

Reviewers recommended that the latest Health Communication Toolkit is found / obtained as soon as possible and that arrangements are made for it to be easily available to staff on both hospital sites. Some 'easy read' literature may be used sufficiently often to be kept on wards. Reviewers suggested that other 'easy read' literature and relevant resources should be stored in a central location that is easily accessible outside of normal working hours.

**How are advocates, families and care providers involved in the process of developing care plans?**

The care plans made available and reviewed at the time of the visit did not evidence engagement with people with learning disabilities, or their families, advocates or care providers.

12. **Are joint care plans developed between the hospital and specialist learning disability services/care providers?**

If the acute liaison nurse was involved then a joint care plan may be developed. At the time of the review visit, 15 people with a learning disability were 'open' to the community learning disabilities service and either in hospital with support or receiving support as part of a desensitisation programme prior to admission.

The Speech and Language Therapists from the acute and community services were in the process of developing a pathway for the care of people with learning disabilities.

## Formative Review Questions

### Preparation for discharge:

13. **How is discharge planning coordinated? How are the person with learning disabilities, their advocates, families and care providers and learning disability specialist services involved in discharge planning?**

See comments to section 21 about the pathways of care. The community learning disabilities service was involved in discharge planning of people known to the service. Complex case discussions could also be triggered.

Reviewers considered there was potential to reduce length of stay by improving the care of people with learning disabilities prior to and during acute hospital admission.

14. **How is information on follow up care communicated to the person with learning disabilities and everyone involved in their care?**

The acute liaison nurses (if they were available) would facilitate this for people with whom they were involved. Otherwise, discharge letters were used with the expectation that accessible communication would be used for the individual if required.

15. **What follow on care after discharge was arranged? Could post-discharge care have been improved?**

Follow-up by the community learning disabilities service took place for people 'open' to the service. Reviewers suggested that an area for improvement would be to ensure that there was post-discharge care for those with a mild learning disability or autism.

16. **What processes exist to address any concerns regarding care and treatment? How well do these work?**

Reviewers saw several 'Root Cause Analyses' that had been undertaken following incidents involving admission to hospital. These were all undertaken by SSSFT with no SaTH involvement. The analyses therefore concentrated on mental health issues, with no comments about ways in which the management of physical health could be improved. All the expected actions were allocated to the acute liaison nurses, which appeared to be expecting a lot given the pressures on this team.

Reviewers strongly recommended that 'Root Cause Analysis' of incidents involving people with learning disabilities admitted to acute hospitals should involve all organisations and should look holistically at mental and physical health.

## Formative Review Questions

### Staff training:

17. **Do staff have training in 'best interests' and Mental Capacity Act (MCA) and, when asked, can they demonstrate a good understanding in relation to caring for a person with learning disabilities?**

Reviewers were told that MCA training was mandatory at SaTH, but the data provided indicated that only 10.8% <sup>1</sup>of staff had completed MCA and Deprivation of Liberty Safeguards (DoLS) training. There had previously been three levels of MCA training which had been changed to two levels. Reviewers were told that uptake by allied health professionals was good, but uptake by ward staff less good.

Ward staff at Princess Royal Hospital had completed appropriate training in caring for a person with learning disabilities. A competence booklet was in place, and had been marked on completion. Staff were able to demonstrate a good understanding of local policies and the action they should take. Staff in the Emergency Department at Royal Shrewsbury Hospital had also completed the competence booklet, but this was not the case for all staff on the other wards that were visited by the reviewers.

A coordinated approach to staff training in the care of people with learning disabilities was not evident. SSSFT had developed the competence booklet. SaTH in conjunction with the local authority had commissioned four sessions of training for hospital staff, the first session of which was being delivered on the day of the visit. Reviewers were told that anyone could attend these sessions. It was not clear what type of training was expected for different groups of staff. Furthermore it was reported to the reviewers that the community learning disabilities service had not been party to the design or delivery of these sessions.

18. **Is on-going learning disability awareness training provided for all health care staff including porters, cleaners, receptionists, senior managers and administrators?**

It was not clear whether these groups of staff were expected to undertake any of the training. Reviewers suggested that a clear framework of expected training should be developed, including training for porters, cleaners, receptionists, senior managers and administrative staff who may have contact with people with learning disabilities.

### Patient feedback:

19. **Is there evidence of feedback from service users with learning disabilities and their carers and families?**

Reviewers did not see any evidence of specific feedback from service users with learning disabilities or their carers and families. The 'Friends and Families Test' was not available in an accessible format and did not specifically identify responses relating to the care of people with learning disabilities.

20. **Is there evidence of actions taken as a result of feedback?**

Reviewers did not see any evidence of actions taken as a result of feedback.

<sup>1</sup> This figure excludes medical staff in training whose MCA and DoLS training compliance was held by the West Midlands Deanery.

## Formative Review Questions

### Other issues:

#### Pathways of care

21. Pathways of care for people with learning disabilities admitted to acute hospitals, and expected processes, were not clear. There was one out of date policy and three pathways for acute hospital care of people with learning disabilities, one of which had been developed by SaTH, one by SSSFT and one, very shortly before the review visit, by the therapy team. The therapy pathway was an integrated pathway, but the SaTH and SSSFT pathways were separate and did not represent integrated pathways of care. It was not clear whether social services had been involved in the development of any of the pathways.

#### Acute Liaison Team

22. The acute liaison team comprised two nurses, one of whom was on long-term sick leave at the time of the review. The other nurse was therefore covering both hospital sites. There did not appear to be a clear office space on either site, or a place where relevant materials could be stored and accessed by staff when the team was not available.

Good arrangements were in place for elective admissions of people with learning disabilities known to the community learning disabilities service, or where the GP included information about a patient's learning disability on the referral letter. The acute liaison nurse received a list of future admissions, including for dental treatment, attended out-patient appointments, provided additional support and identified reasonable adjustments that were needed.

Support for people with learning disabilities admitted as emergencies was less good and there was insufficient time for the acute liaison nurse to be proactive in supporting these patients. The acute liaison nurses would respond if asked, or if they noticed a patient on a ward, but this was mainly reactive.

It was not clear whether the acute liaison nurses had permission to write in SaTH medical and nursing notes. Reviewers were told by senior managers that this was allowed, but were also told that this was challenged by clinical staff. The notes seen by reviewers said that patients had been seen by the acute liaison nurse, but there were no details of actions taken or recommended.

Clinical notes and activity data for the acute liaison team were recorded on the SSSFT RiO system. Access to this system was not available on the hospital sites and so the nurses went to Oak House or their base in Telford to record this information.

#### Keeping up to date

23. The 'Guidelines for the care of adults with a learning disability on admission to The Shrewsbury and Telford Hospital NHS Trust' (agreed by all local organisations) had been due for review in May 2015. The competency book, the communication toolkit in use at the time of the visit and the hospital 'passport' were also all out of date. Reviewers were particularly concerned that the latest Health Communication Toolkit was not being used.

## Formative Review Questions

### Data Collection

24. The number of people with a learning disability admitted to SaTH was not clear. Data were available on the number known to the community learning disabilities service (15 at the time of the visit). It was not clear how acute liaison team activity relating to people with learning disabilities who were not known to the community learning disabilities service was counted. As a result of the lack of 'flagging' (see question 2), there was no information on the number of people with learning disabilities who were admitted but not referred to the acute liaison team. The provision of general advice and support, and staff training, may therefore be under-recorded.

### Oak House, South Staffordshire and Shropshire Healthcare NHS Foundation Trust

25. At the time of the review visit, Oak House was a 10-bedded respite unit on the RSH site for people with moderate learning disabilities. Reviewers considered that the action plan following this review provided the opportunity to look at the role of Oak House as well as that of the acute liaison team. Health facilitation, acute liaison and care of people with learning disabilities who also have complex physical health needs could be looked at together. It would be essential that primary and secondary physical health care services, as well as the SSSFT and local authority services for people with learning disabilities, are all involved in this work.

### Commissioning

26. There was no service specification or key performance indicators (KPIs) for the acute liaison team, and it was not clear what role commissioners expected this service to fulfil. Reviewers suggested that KPIs could include, for example, response time and outcome measures. Arrangements for the quality assurance of the work of the team, by commissioners or providers, were also not clear. Hospital benchmarking standards, for example the National Audit of Learning Disabilities Standards 2013 and 2014, could be used for this purpose.

### Partnership Boards

27. Reviewers were told that both Shropshire and Telford & Wrekin had thriving Learning Disability Partnership Boards. Reviewers did not meet anyone from the Partnership Boards but suggested that these forums could be used for taking forward the issues identified in this report.

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## APPENDIX 1 MEMBERSHIP OF VISITING TEAM

### Visiting Team

Susan Brady	Community Learning Disability Nurse	Black Country Partnership NHS Foundation Trust
Jade Brooks	Deputy Director of Operations	NHS Herefordshire CCG
Ree Jeffries	Operational Manager / Clinical Lead for Learning Disabilities	2gether NHS Foundation Trust
Dr Sunny Kalsy-Lillico	Lead Consultant / Clinical Psychologist	Birmingham Community Healthcare NHS Trust
Julia Kelly	Lead Nurse - PAMHS	Black Country Partnership NHS Foundation Trust

### WMQRS Team

Jane Eminson	Director	West Midlands Quality Review Service
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