Improving Acute Hospital Care for Adults with a Learning Disability and Adults with Autism in the East of England

A Review of the Acute Hospital Self Assessments and Improvement Plans
September 2012

An NHS in the east of England QIPP project
Foreword

In the east of England, the 17 acute hospital Trusts have been working with their commissioners and Learning Disability Partnership Boards to carry out self assessments of their services for these patients and to agree plans for 2012 - 2014 to improve those services.

This report describes the outcomes of the self assessments and gives us a picture of what the self improvement plans should deliver.

Importantly, it provides Top Tips for improving services and a Dashboard of Improvement, Quality and Efficiency Measures. These have been developed from learning and innovation across the east of England. Along with acute hospital Trust Boards and commissioners, Health and Well Being Boards and Learning Disability Partnership Boards will be able to use the Dashboard to effectively monitor and scrutinise the difference being made to people's care, their health outcomes and their experience as patients.

The report also cross references the Monitor Compliance Framework with the acute hospital self assessment framework, enabling Foundation Trusts and aspiring Foundation Trusts to evidence their work to meet Monitor requirements.

There are important recommendations in the Executive Summary for acute hospital Trusts and commissioners. Implementing these should be a core part of acute hospital service improvement for 2012 - 2014. Leadership by acute Trust managers, clinicians, Primary Care Trusts and Clinical Commissioning Groups in partnership with service users and family carers is the key to achieving this.

By providing leadership and working in partnership, the work described in this report and its recommendations give us a firm basis over the next two years, for delivering high quality, person centred, safe acute hospital services for adults with a learning disability and adults with autism.

You can access this report through this link:

https://www.eoe.nhs.uk/page.php?page_id=2159

An easy read version of this document is also available through this link.

Ruth May
Nurse Director
NHS Midlands and East
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1. Executive Summary

The NHS in the east of England has been committed to improving the health and well being of people with a learning disability over several years. This commitment was reinforced by the publication of Death by Indifference by Mencap (2007) and the Michael Report: Healthcare for All (2009). Both reports revealed significant and, at times, shocking deficits in the healthcare of people with a learning disability receive, particularly the care provided.

Alongside this, the implementation of Fulfilling and Rewarding Lives, the national strategy for autism, has led to an increasing focus on the care of adults with autism.

As part of an east of England Quality, Innovation, Productivity and Prevention (QIPP) project, the 17 acute hospital Trusts in the east of England have each undertaken a self assessment and developed a 2012-14 improvement plan to deliver better, safer care for adults with a learning disability and adults with autism.

People with a learning disability and people with both a learning disability and autism are generally better known to services. However, people with autism alone are a ‘hidden’ group of people not only for acute hospital Trusts but for most public services, a situation being addressed by the local autism strategies being drawn up in 2012/13. This QIPP work has supported Trusts to plan how they will meet the needs of adults with autism in the future.

The self assessments and improvement plans have been validated by PCTs and Learning Disability Partnership Boards with the involvement in some areas of Clinical Commissioning Groups. Whilst this work was underway, its importance was reinforced by the publication in 2012 of a follow up report by Mencap ‘Death by Indifference: 74 Deaths and Counting’. The report highlights continued concerns and risks for people and concludes that ‘although some positive steps have been taken in the NHS, many health professionals are still failing to provide adequate care to people with a learning disability’.

This report provides:

- A detailed review and commentary on the acute hospital self assessments, including areas of concern
- A review of the improvement plans and their expected impact
- A revised set of Top Tips for delivering high quality acute hospital services for these groups of people
- A Dashboard of Improvement, Quality and Efficiency Measures
- A mapping of the Self Assessment Framework against the Monitor Compliance Framework indicator for NHS Foundation Trusts specifically concerned with access to healthcare for people with a learning disability.
THE SELF ASSESSMENTS AND AREAS OF CONCERN

The self assessments by the acute Trusts provide a mixed picture across the east of England. The validated self assessment RAG ratings for all the acute hospital Trusts are set out in Appendix 1. There are many examples of excellent practice across the region which should be built on. These are summarised in Appendix 2. The two appendices will be usefully read alongside each other.

The overall picture though is that there remains much to be done. On the basis that all Trusts should be aiming to achieve ratings of Amber/Green or Green, any objective rated Amber and below should be a priority for improvement over the next two years. On a regional basis, 15 out of the 23 objectives in the self assessment framework are rated Amber and below. Chapter 3 sets out the broad areas of concern whilst Appendix 3 provides a detailed commentary for each objective on the current position in the east of England.

The east of England Vision for Better Health and Well Being for People with a Learning Disability and their Families 2011-2021 gave a commitment that by 2012: ‘all acute hospitals will have learning disability liaison nurses appointed and all acute hospitals will have systems to monitor and report on the effectiveness of the reasonable adjustments put in place’. All acute hospital Trusts now have a learning disability liaison nurse or (for one) a disability advisor in place. However, only two Trusts have developed audit tools which include the audit of reasonable adjustments.

Recommendation: The east of England A2A network should draw up and distribute options and guidance for Trusts on undertaking audits of reasonable adjustments.

THE IMPROVEMENT PLANS AND THEIR EXPECTED IMPACT

All the improvement plans are comprehensive and address those objectives which have been rated Amber and below. An analysis of the information provided by 6 Trusts (in Chapter 4) indicates that by 2014, it can be expected that the position on an aggregate basis across the east of England will be a rating of Amber/Green or Green on all 23 objectives.

To address the needs of adults with autism the report notes that for most Trusts, involvement in their local autism strategy work is central to being able to take this forward.

It is noticeable that undertaking these self assessments and agreeing improvement plans has already driven a range of improvements e.g. raised awareness at Executive Team and Board level; clinical leadership emerging; clinical audit, information system specialists and clinical leads becoming engaged in delivering improvements. However, the report notes that a significant risk to the implementation of the improvement plans over the next two years is a loss of leadership and ownership across the Acute Trust over time and an over reliance on the liaison nurse or disability advisor to deliver the improvement plan without broad corporate involvement and support.

Recommendation: Acute Trust Boards should identify a non-Executive lead and a senior clinical lead for learning disability/autism as well as an Executive lead, and that regular reports on the implementation of the improvement plan and the recommended Dashboard measures are provided with contributions from all relevant teams in the Trust.

The report also notes that the move of commissioning responsibilities to Clinical Commissioning Groups potentially poses a significant risk of acute hospital commissioners losing sight of the self assessments and the implementation of the improvement plans.

Recommendation: that PCTs work with Clinical Commissioning Groups to ensure that future acute hospital commissioners include the delivery of improvement plans in performance reviews and CQUIN agreements.
A LEARNING DISABILITY/ AUTISM DASHBOARD

Making sure that the improvement plans are delivering better quality care, with health outcomes comparable with the rest of the Trust’s patients and consequently delivering greater efficiencies in services is the central purpose of this work. Currently, it is difficult to provide evidence that these are being achieved.

Chapter 6 sets out a Learning Disability / Autism Dashboard of Measures which, if an electronic learning disability/autism flag is in place, will provide information to check that improvements in quality and outcomes as well as efficiencies are being delivered. The majority of this information is already being collected for the general hospital population.

Recommendation: Health and Well Being Boards, Learning Disability Partnership Boards, acute hospital Trust Boards and commissioners should receive annual or more regular reports of the Learning Disability/Autism Dashboard of Improvement, Quality and Efficiency Measures so that they can effectively monitor and scrutinise the difference being made to people’s care, their health outcomes, their experience as patients and the efficiencies being achieved.

TOP TIPS FOR DELIVERING HIGH QUALITY ACUTE HOSPITAL SERVICES FOR THESE GROUPS OF PEOPLE

The Top Tips provided in the original QIPP report have been revised to capture the learning from the self assessments and improvement plans across the east of England (Chapter 5).

Recommended: acute Trusts should now review and update their improvement plans against the Top Tips to ensure that they include the best practice and learning from across the east of England and maximise all the Quality, Innovation, Productivity and Prevention outcomes available.

MAPPING THE FRAMEWORK AGAINST THE MONITOR COMPLIANCE FRAMEWORK INDICATOR FOR LEARNING DISABILITY

The Self Assessment Framework has been mapped against the 2012/13 Monitor Compliance Framework indicator 18 (Chapter 7). This indicator is specifically concerned with access to healthcare for people with a learning disability. The mapping enables both acute hospital and community health service Foundation Trusts and aspirant Foundation Trusts to provide clear evidence that they are meeting the Monitor requirements.

Recommended: that both acute hospital and community health service Foundation Trusts and aspirant Foundation Trusts use the Monitor Compliance Framework mapping tool to provide clear evidence that they are meeting the Monitor requirements.
Summary of the recommendations

THE SELF ASSESSMENTS AND AREAS OF CONCERN

Developing an audit tool for reasonable adjustments.

**Recommendation:** The east of England A2A network should draw up and distribute options and guidance for Trusts on undertaking audits of reasonable adjustments.

THE IMPROVEMENT PLANS AND THEIR EXPECTED IMPACT

Ensuring leadership and ownership for improving services over the long term.

**Recommendation:** Acute Trust Boards should identify a non-Executive lead and a senior clinical lead for learning disability/autism as well as an Executive lead, and that regular reports on the implementation of the improvement plan and the recommended Dashboard measures are provided with contributions from all relevant teams in the Trust.

**Recommendation:** that PCTs work with Clinical Commissioning Groups to ensure that future acute hospital commissioners include the delivery of improvement plans in performance reviews and CQUIN agreements.

TOP TIPS FOR DELIVERING HIGH QUALITY ACUTE HOSPITAL SERVICES FOR THESE GROUPS OF PEOPLE

Reviewing the improvement plans against the Top Tips.

**Recommendation:** acute Trusts should now review and update their improvement plans against the Top Tips to ensure that they include the best practice and learning from across the east of England and maximise all the Quality, Innovation, Productivity and Prevention outcomes available.

A LEARNING DISABILITY/AUTISM DASHBOARD

Making sure the plans improve people’s care and health, their experience as patients and deliver efficiencies.

**Recommendation:** Health and Well Being Boards, Learning Disability Partnership Boards, acute hospital Trust Boards and commissioners should receive annual or more regular reports of the Learning Disability/Autism Dashboard of Improvement, Quality and Efficiency Measures so that they can effectively monitor and scrutinise the difference being made to people’s care, their health outcomes, their experience as patients and the efficiencies being achieved.

MAPPING THE FRAMEWORK AGAINST THE MONITOR COMPLIANCE FRAMEWORK INDICATOR FOR LEARNING DISABILITY

Providing evidence that Monitor requirements are being met.

**Recommendation:** that both acute hospital and community health service Foundation Trusts and aspirant Foundation Trusts use the Monitor Compliance Framework mapping tool to provide clear evidence that they are meeting the Monitor requirements.
The NHS in the east of England has been committed to improving the health and well being of people with a learning disability over several years. This commitment was reinforced by the publication of Death by Indifference by Mencap (2007) and the Michael Report: Healthcare for All (2009). Both reports revealed significant and, at times, shocking deficits in the healthcare people with a learning disability receive and particularly the care provided by acute hospitals.

NHS East of England established a Quality, Innovation, Productivity and Prevention (QIPP) project in 2010 to improve acute hospital pathways for adults with a learning disability and adults with autism, with a report providing guidance and frameworks agreed and published in April 2011. The report is available here:

https://www.eoe.nhs.uk/page.php?page_id=2159

Alongside this, the east of England Vision for Better Health and Well Being for People with a Learning Disability and their Families 2011-2021 was agreed in March 2011, with a commitment that by 2012: ‘all acute hospitals will have learning disability liaison nurses appointed and all acute hospitals will have systems to monitor and report on the effectiveness of the reasonable adjustments put in place.’

In the east of England, Learning Disability Liaison Nurses and a Disability Advisor meet regularly and are members of the national A2A network. A2A aims to support networking and sharing of good practice amongst professionals who have a role in supporting people with learning disabilities to access healthcare services in general hospital settings.

The importance of improving acute hospital care for people with a learning disability has been re-emphasised by the publication by Mencap of ‘Death by Indifference: 74 Deaths and Counting’ in January 2012. The report identifies that ‘although some positive steps have been taken in the NHS, many health professionals are still failing to provide adequate care to people with a learning disability’. The report highlights the deaths of 74 people with a learning disability in NHS care over the last ten years, 59 of them in the last 5 years.

In 2011, all the 17 Acute Hospital NHS Trusts and Foundation Trusts in the east of England were asked to complete a self assessment and improvement plan using the framework in the QIPP report.

By August 2012, the self assessments and RAG ratings of all 17 Trusts had been validated and 16 Trusts have had their improvement plans validated. One Trust is in discussion with their commissioners and Partnership Board to finalise their improvement plan. Validation has been by PCTs and Learning Disability Partnership Boards with, wherever possible, Clinical Commissioning Group involvement. The 16 agreed validated self assessments and improvement plans have been agreed by Acute Trust Boards.
The Self Assessment Framework consists of 6 top targets and 23 objectives.

The objectives have each been rated on a scale of Red; Red/Amber; Amber; Amber/Green; Green.

The self assessment RAG ratings of all the acute hospital Trusts is given in Appendix 1.

The overall picture in the east of England is shown right:

| Top Target 1: Leadership, management and strategy | 3 objectives: | 3 |
| Top Target 2: Care standards, reasonable adjustments and service delivery | 7 objectives: | 6 1 |
| Top Target 3: Pathways | 4 objectives: | 3 1 |
| Top Target 4: Involvement and representation of people with a learning disability/autism and their family carers | 3 objectives: | 1 1 1 |
| Top Target 5: Information for people with a learning disability/autism and their family carers | 3 objectives: | 1 1 1 |
| Top Target 6: Keeping people safe | 3 objectives: | 2 1 |

**TOTALS**

|  | 2 | 13 | 8 |
Given that services should expect to be of a high quality (indicated by Amber/Green or Green ratings) it is a concern that 15 out of 23 objectives are rated on an east of England basis at Amber or below. Chapter 4 looks at whether improvement plans will bring these objectives up to ratings which indicate high quality of service.

The broad areas of concern identified from the self assessments are:

- Trust Boards not having reporting systems in place to understand the quality of care being delivered to adults with a learning disability/autism specifically, nor the improvements being achieved in the service for these groups of people.

- Inconsistency in the delivery of high standards of fundamental care, comprehensive risk assessments and appropriate nutrition and hydration to every patient with a learning disability and/or autism.

- Difficulties in identifying people before admission, whilst in hospital and during discharge as potentially needing reasonable adjustments throughout their pathways of care and treatment.

- Lack of capacity to deliver training to all the relevant staff.

- Inconsistency in the involvement of people with a learning disability/autism and their family carers in planning their care and providing appropriate information for them.

- Staff not having ready access to resources to make reasonable adjustments and a lack of administrative and information systems to support them in this.

- A possible under reporting of serious and untoward incidents or deaths, near misses and safeguarding incidents involving adults with a learning disability or autism.

In addition, at the time of the self assessments, very few Trusts were engaged with local work to plan and implement a local autism strategy. This is key to effectively extending improvements in access and outcomes to adults with autism. However, most improvement plans include this as an action.

In relation to the commitment in the east of England Vision for Better Health and Well Being for People with a Learning Disability and their Families that by 2012: ‘all acute hospitals will have learning disability liaison nurses appointed and all acute hospitals will have systems to monitor and report on the effectiveness of the reasonable adjustments put in place.’

- All Trusts do have a learning disability liaison nurse or (for one Trust) a Disability Advisor place with a few Trusts having more than one post. In 15 Trusts the posts are substantive and full time. However, one Trust has a part time post on a 1 year contract, and another has a full time post with consideration currently being given to the length of contract.

- Two Trusts have developed audit tools which include the audit of reasonable adjustments.

Recommendation: the east of England A2A network should draw up and distribute options and guidance for Trusts on undertaking audits of reasonable adjustments.
4. The expected RAG ratings in 2014

All the plans are comprehensive and address those objectives which have been rated Amber and below.

As shown in Chapter 3, 15 of 23 objectives are rated Amber and below when aggregated across the east of England. These should be the priority areas for improvement.

Acute Trusts were asked in the guidance for validating improvement plans to give the rating which they expect their improvement plan to deliver for each objective. Six Trusts have provided this information.

As the current RAG rating of the six Trusts for these 15 objectives is either the same or slightly below the overall east of England rating it can be expected that improvements in RAG ratings in these Trusts will be replicated across the east of England.

An analysis of the expected impact of the agreed improvement plans for the six Trusts shows that, on an aggregate basis, all of these 15 objectives should move up to Amber/Green or Green. The detailed analysis is given in Appendix 4.

It should be noted that there are two significant risks to effectively implementing the improvement plans over the next two years:

- A loss of leadership and ownership across the Acute Trust over time, with the liaison nurse/disability advisor expected to deliver the improvement plan without effective corporate leadership or the involvement of other Trust colleagues to deliver various elements of the plan e.g. audit teams; IT and information management colleagues, clinical leads.

Recommendation: Acute Trust Boards should identify a non-Executive lead and a senior clinical lead for learning disability/autism as well as an Executive lead, and that regular reports on the implementation of the improvement plan and the recommended Dashboard measures are provided with contributions from all relevant teams in the Trust.

- Commissioners of acute hospitals losing sight of this work as commissioning moves to Clinical Commissioning Groups with the improvement plans not being included in performance reviews and CQUIN agreements.

Recommendation: that PCTs work with Clinical Commissioning Groups to ensure that future acute hospital commissioners include the delivery of improvement plans in performance reviews and CQUIN agreements.
The Top Tips for delivering high quality acute hospital services for people with a learning disability/autism

Review of the improvement plans has shown that there are sixteen Top Tips for acute hospitals to improve their services.

These Top Tips capture learning from all 17 acute Trusts in the east of England and should be addressed in each Trusts’ improvement plan.

Recommendation: acute Trusts should now review and update their improvement plans against the Top Tips to ensure that they include the best practice and learning from across the east of England and maximise all the Quality, Innovation, Productivity and Prevention outcomes available.

The Top Tips for delivering high quality acute hospital services

1. Embed adults with a learning disability, adults with autism and family carers in the planning and evaluation of services.

2. Provide corporate leadership with designated Non-Executive, Executive Director and senior clinical leads, and at least annual reports to the Trust Board (or Board Committee) and Learning Disability Partnership Board on progress in implementing the improvement plan.

3. Use the Dashboard of measures to find out, report on and scrutinise the difference the improvement plan is making to people’s care, their health outcomes and their experience.

4. Have an electronic flagging system on the patient information system to ensure that staff have an alert that someone may need reasonable adjustments to be made and so that patients’ progress through the pathway can be followed.

5. Use the electronic flag to monitor and act on:
   - Serious incidents and complaints.
   - Extended lengths of stay.

   - Readmissions (within and after 30 days).
   - People who did not arrive.
   - Use of A&E services to improve quality and deliver savings and efficiencies. Compare these to the general hospital population.

6. Audit what is happening specifically for adults with a learning disability and/or autism as part of your ‘business as usual’ audit work:
   - Nutrition and hydration.
   - Risk assessment.
   - Fundamental care. Compare them with comparable groups of patients.

7. Make sure your staff report all serious and untoward incidents or deaths, near misses and safeguarding incidents involving adults with a learning disability or autism and that they understand the risks of:
   - Diagnostic overshadowing (‘he had this health problem because of his learning disability’).
   - Not making reasonable adjustments (‘we didn’t know she needed to eat and drink in this particular way’).
8. Agree patient pathways, particularly for key areas:
   - A&E.
   - Elective care.
   - Outpatients.
   - Radiology.
   - Theatre.
   - Phlebotomy
   and embed them in policy and guidance.

9. Ensure that your staff have a wide range of resources to make reasonable adjustments and hospital systems which support them to do this, particularly around:
   - Preparation for admission.
   - Appointment systems.
   - Communication.
   - Easy read information.

10. Provide the right levels of training for your staff; have self advocates and family carers involved in delivering the training; and formalise the roles and responsibilities of your learning disability link staff

11. Make sure that your hospitals’ learning disability liaison nurse is reporting to someone of sufficient seniority corporately to act on issues relating to learning disability and autism, particularly safety and risk.

12. Have an agreed protocol with community learning disability services and, if possible, GPs regarding expectations and roles pre-admission and discharge

13. Engage with work on the autism strategy for your local area

14. Agree a Transition Policy for young people (not only learning disability or autism) who are transferring from paediatric services to adult services.

15. Make sure your maternity services are meeting the needs of women and partners with a learning disability or autism, identifying a lead midwife and monitoring the use and outcomes of the service.

16. Enable people with a learning disability or autism to join the Trust’s workforce by adopting the Project Search approach.
Having agreed the improvement plan, it is important that everyone can see if it is making a difference.

The self assessments and improvement plans show that, having achieved an electronic learning disability/autism flag on their patient information system, acute hospitals will be able to provide a range of information about progress in delivering the improvement plan, the quality of care people receive, comparisons with the broader hospital patient population, and the efficiencies which can be achieved.

A Dashboard of Improvement, Quality and Efficiency measures is set out in this chapter. The majority of the information can be gathered through current informatics work, although some Trusts will need to develop an audit of reasonable adjustments and ways of effectively getting feedback from people about the care and treatment they have received.

The Dashboard will enable Acute Trusts, commissioners, Health and Well Being Boards, and Learning Disability Partnership Boards to monitor and scrutinise the difference the improvement plan is making to people's care, their health outcomes and their experience as patients.

**Recommendation:** Health and Well Being Boards, Learning Disability Partnership Boards, acute hospital Trust Boards and commissioners should receive annual or more regular reports of the Learning Disability/Autism Dashboard of Improvement, Quality and Efficiency Measures so that they can effectively monitor and scrutinise the difference being made to people's care, their health outcomes, their experience as patients and the efficiencies being achieved.
Measures which are used by all Acute Trusts:

1. Effective care for people with a learning disability or autism from patient care audits:
   - fundamental care
   - nutrition and hydration
   - risk.

2. Activity information for A&E; emergency and elective admissions; outpatients:
   - Repeat attendances at A&E
   - Numbers of readmissions (within and after 30 days)
   - ‘did not arrive’
   - extended length of stay

3. Complaints / compliments made.

4. Serious incidents and safeguarding referrals.

All of these can be reported as:

- raw figures for people with a learning disability or autism

and

- as a percentage of the numbers of people with a learning disability or autism using the Trust services compared to the overall rate for patients

Measures currently collected by some but not all Acute Trusts:

1. An audit of the reasonable adjustments being made (see section 2.2 in the Good Practice chapter for examples of work in this area) and the earlier recommendation for an east of England wide piece of work on an audit tool for reasonable adjustments.

2. Numbers of staff using or attending relevant training.

3. Involvement of and feedback from people with a learning disability or autism and family carers (see sections 4.1 and 6.3 in the Good Practice chapter for examples of work in this area).
7. Mapping the Acute Hospital Self Assessment Framework against the Monitor Compliance Framework 2012/13

The information provided is used by Monitor to assess the risk of a Trust failing to comply with its Authorisation. The full Compliance Framework is available here:


The Compliance Framework includes a set of indicators to assess the quality of governance at NHS Foundation Trusts. Indicator 18 is specifically concerned with access to healthcare for people with a learning disability. It is detailed on pages 46 and 56 of the document.

The indicator sets out six criteria for meeting the needs of people with a learning disability, based on recommendations set out in Healthcare for All (DH, 2008).

The criteria are:

1. Does the NHS trust have a mechanism in place to identify and flag patients with learning disabilities and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?

2. Does the trust provide readily available and comprehensible information to patients with learning disabilities about the following criteria:
   - treatment options;
   - complaints procedures; and
   - appointments

3. Does the trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities?

4. Does the trust have protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff?

5. Does the trust have protocols in place to encourage representation of people with learning disabilities and their family carers?

6. Does the trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports?

The Learning Disability Self Assessment Framework enables Foundation Trusts’ to provide clear evidence that they are meeting each of these broad criteria. The following table maps the objectives in the self assessment against each of the criteria.

Those objectives in italics provide evidence for more than one of the criteria.

**Recommendation:** that both acute hospital and community health service Foundation Trusts and aspirant Foundation Trusts use the Monitor Compliance Framework mapping tool to provide clear evidence that they are meeting the Monitor requirements.
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<th>NO</th>
<th>REQUIREMENT</th>
<th>EVIDENCE AVAILABLE THROUGH THESE SELF ASSESSMENT OBJECTIVES</th>
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<tr>
<td>1</td>
<td>Does the NHS trust have a mechanism in place to identify and flag patients with learning disabilities and Protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients?</td>
<td>2.5 Adults with learning disabilities or autism are identified on referral to the Trust and through Trust information systems. 1.2 The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism. 2.1 <em>The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse)</em> and identifies practitioners with extra skills and responsibilities for adults with learning disabilities or autism. 2.2 The Trusts’ plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disabilities or autism. 2.3 Adults with learning disabilities or autism receive high standards of fundamental care. 2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs. 2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration. 2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments. 3.2 Adults with learning disabilities or autism attend A&amp;E appropriately. 3.3 Adults with learning disabilities or autism are discharged home in a safe and timely way. 3.4 Women and partners with learning disabilities or autism have a clear pathway for use of maternity services. 4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery.</td>
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| 2  | Does the trust provide readily available and comprehensible information to patients with learning disabilities about the following criteria:  
  - treatment options;  
  - complaints procedures; and  
  - appointments. | 3.1 Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately  
  5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions  
  5.2 All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.  
  5.3 People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback. | NO | |
| 3  | Does the trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities? | 4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery. | NO | |
| 4  | Does the trust have protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff? | 2.1 The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for adults with learning disabilities or autism.  
  2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to all Community Health Trust staff. | NO | |

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**EVIDENCE AVAILABLE THROUGH THESE SELF ASSESSMENT OBJECTIVES**

- **3.1** Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately.
- **5.1** People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions.
- **5.2** All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.
- **5.3** People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback.
- **4.2** Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery.

**RAG FOR EACH OBJECTIVE**

- NO

**OVERALL MONITOR RAG**

- NO
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<th>OVERALL MONITOR RAG</th>
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| 5  | Does the trust have protocols in place to encourage representation of people with learning disabilities and their family carers? | 4.1 Adults with learning disabilities or autism and their family carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation.  
4.3 People with learning disabilities or autism are represented in the workforce.                                                                                                                                  |                        |                     |
| 6  | Does the trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports? | 1.1 There is clearly identifiable Board and senior management engagement in embedding a strategy for adults with a learning disability or autism.  
1.3 Partnership Working takes place at all levels within the organisation.  
2.3 Adults with learning disabilities or autism receive high standards of fundamental care.  
2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.  
2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration.  
2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments.  
6.1 The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism.  
6.2 The Trust demonstrates learning from other incidents involving people with learning disability or autism  
6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this. patients with learning disabilities? |                        |                     |
1. LEADERSHIP, MANAGEMENT AND STRATEGY

1.1 There is clearly identifiable Board and senior management engagement in embedding a strategy for adults with a learning disability or autism.

1.2 The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism.

1.3 Partnership working takes place at all levels within the organisation.

### Appendix 1: The self assessment RAG ratings of the seventeen acute hospital Trusts for all objectives

<table>
<thead>
<tr>
<th>1. LEADERSHIP, MANAGEMENT AND STRATEGY</th>
<th>Bedford</th>
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</table>
2. CARE STANDARDS, REASONABLE ADJUSTMENTS AND SERVICE DELIVERY

2.1 The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for adults with learning disabilities or autism.

2.2 The Trusts’ plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disabilities or autism.

2.3 Adults with learning disabilities or autism receive high standards of fundamental care.

2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.
### 2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration.

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### 2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments.

### 2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to all hospital staff.

<table>
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</table>
### 3. PATHWAYS

|  | Bedford | Luton & Dunstable | Addenbrookes | Hinchingbrooke | James Paget | West Herts | East & North Herts | Ipswich | West Suffolk | Norfolk & Norwich | Queen Elizabeth’s Lynn | Peterborough & Stamford | Basildon & Thurrock | Southend | Colchester | Mid Essex | The Princess Alexandra Hospital Harlow | East of England |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **3.1** Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately. | | | | | | | | | | | | | | | | | | |
| **3.2** Adults with learning disabilities or autism attend A&E appropriately. | | | | | | | | | | | | | | | | | | |
| **3.3** Adults with learning disabilities or autism are discharged home in a safe and timely way. | | | | | | | | | | | | | | | | | | |
| **3.4** Women and partners with learning disabilities or autism have a clear pathway for use of maternity services. | | | | | | | | | | | | | | | | | | |
## 4. INVOLVEMENT AND REPRESENTATION OF PEOPLE WITH LEARNING DISABILITY AND THEIR CARERS.

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<tr>
<td>4.1</td>
<td>Adults with learning disabilities or autism and their family carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation.</td>
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<td>4.2</td>
<td>Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery.</td>
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<td>4.3</td>
<td>People with learning disabilities or autism are represented in the workforce.</td>
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5. INFORMATION FOR PEOPLE WITH LEARNING DISABILITY AND THEIR CARERS.

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</table>

5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions.

5.2 All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.

5.3 People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback.
6. Keeping people safe

<table>
<thead>
<tr>
<th>6.1 The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism.</th>
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<table>
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<th>6.2 The Trust demonstrates learning from other incidents involving people with learning disability or autism.</th>
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<tr>
<th>6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this.</th>
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</table>
Appendix 2: Examples of Good Practice and Innovation from the Acute Trust Self Assessments

These examples of good practice and innovation are drawn from the self assessment documents validated by commissioners and Learning Disability Partnership Boards. It is not totally comprehensive as developments have continued since self assessments were validated and the level of detail in the self assessments does not always capture the good practice in place. Sometimes, details have been given verbally at validation rather than in documentation. This section includes links to some of the good practice documents highlighted in the text. Double click on the paper clip to open the document.

1. Leadership, management and strategy

<table>
<thead>
<tr>
<th>1.1 There is clearly identifiable Board and senior management engagement in embedding a strategy for adults with a learning disability or autism.</th>
<th>Addenbrookes; Ipswich; Luton and Dunstable; West Suffolk; Mid Essex: all have non-Executive Directors on the Trust Board responsible for either Learning Disability or Vulnerable Adults. Norfolk and Norwich: LD strategy, developed in 2006, has been continuously updated. Action plan in place. Ratified by Director of Nursing and results reported annually to the Board. Queen Elizabeth: The QEH Learning Disability Steering Group, chaired by the Deputy Director of Nursing, has an annual work plan with clear, identified goals and submits an annual report to the Healthcare Governance Committee, a sub-committee of the Board. 11 Trusts have an electronic learning disability flag system in place and are able to provide varying numbers of reports on learning disability: Addenbrookes; Ipswich; Luton and Dunstable; Norfolk and Norwich; West Suffolk; West Herts; Bedford; Peterborough and Stamford; Basildon and Thurrock; Southend; James Paget.</th>
</tr>
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<tbody>
<tr>
<td>1.2 The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism.</td>
<td>Addenbrookes: Has an agreed Adolescent Transition in Care Guidelines. Queen Elizabeth: The Trust has in place a policy and an agreed pathway for the management of patients with a learning disability.</td>
</tr>
<tr>
<td>1.3 Partnership Working takes place at all levels within the organisation.</td>
<td>Queen Elizabeth: The Trust has submitted two annual reports to the Cambridge Council Health &amp; Adult Social Care Scrutiny Committee to demonstrate the Trust’s levels of compliance with the council’s strategy for improving services for people with a learning disability. West Herts: • Safeguarding nurse and other Trust staff attend the Care Pathway Group for Children with Special Needs chaired by Paediatric Consultant, working in partnership with school nurse and transition team to improve hospital care within acute adult environment for young people over age of 16. • The West Hertfordshire End of Life Care Group, chaired by Learning Disability Health Liaison Nurse, is attended by Macmillan nurse working with the LD community who may be in last year of life and with Hospice Medical leads to produced specific care pathway documentation.</td>
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</table>
2. Care standards, reasonable adjustments and service delivery

| **2.1** The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for adults with learning disabilities or autism. | **Ipswich:** There are 40 Link Professionals with a specific role description. 
[Learning Disabilities/Autism Link Practitioner Role Description](#)  
**James Paget:** has an agreed job description and person specification for its Learning Disability/Autism Link Practitioners. Link Practitioners have been identified for all wards and departments. 
[Learning Disabilities/Autism and Safeguarding Vulnerable Adults Link Practitioner Role Description](#)  
**Peterborough and Stamford:** have agreed a protocol with GPs which includes the expectations when referring people with a learning disability to hospital. 
[GP Practice Step By Step Protocol - To Develop and Deliver Annual Health Checks for People with Learning Disabilities](#) |
| --- | --- |
| **2.2** The Trusts’ plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disabilities or autism. | **Luton and Dunstable:** Notes audit included and demonstrated some evidence of reasonable adjustments.  
**Addenbrookes:** has developed an audit tool which includes reasonable adjustments, fundamental care and the use of hospital passports.  
**West Suffolk:**  
- The Trust’s Equality and Diversity plan to deliver the Public Sector Equality Duty has 5 objectives, 1 of which is specifically aimed to improve the care of people with a learning disability.  
- The Trust has an alert system that allows identification of people with a learning disability and the PAS also identifies ethnic background of patients if this is supplied to us by the patient. It is therefore possible to link the two to provide information.  
**Mid Essex:** Single Equality Scheme action plan is in place and this includes people with learning disabilities.  
**Queen Elizabeth:** The Trust commitment to making reasonable adjustments to meet the needs of patients with a learning disability or autism is referenced in the Single Equality Scheme but articulated in detail in the Policy and Procedure for the Management of patients with a Learning Disability.  
**James Paget:** has a draft protocol for the respective roles and responsibilities of the Community Learning Disability Team and the acute hospital Trust. The protocol is currently being signed off. |
### 2.3 Adults with learning disabilities or autism receive high standards of fundamental care.

**West Herts; East & North Herts:** Purple folders are carried by people with LD giving detailed information about people’s health needs. This includes the person’s hospital passport. Trust staff receiving awareness training of purpose and how to use the Purple folder.

**Addenbrookes:** has developed an audit tool which includes reasonable adjustments, fundamental care and the use of hospital passports.

**Ipswich:** Patient experience quality outcomes are currently defined within CQUIN and the acute contract includes specific objectives on access to healthcare for adults with a learning disability.

**Luton and Dunstable:** Outcomes for CQUIN were defined in 2011/12 scheme and are to be rolled over/repeated in 2012/13.

**Norfolk and Norwich:** Health books are used during hospital stays when brought in. Nursing documentation makes specific reference to vulnerable adults requiring additional support.

**Basildon and Thurrock:** Have Specialist Assessment Forms (adult and children) for staff to complete in conjunction with their Hospital Passport. They are ward transferable and also can be used if patient is readmitted within 7 days with the same medical need. The forms are stored at both ward level, and easily and readily available on the Intranet. The underlying principle of the form is to inform staff care for the patients of important, information on the patient and how best to provide support.

[Specialist Assessment Form - Adults](#)
[Specialist Assessment Form - Paediatric](#)

### 2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.

**Bedford:** Patients have core risk assessment completed on admission to hospital. These assessments do identify if the person has a Learning Disability or lacks mental capacity or has specific communication problems.

**Luton and Dunstable:** Patient initial assessment documentation has a Cognitive Impairment section which includes: the identification of Learning Disability patients; if they have an All About Me care plan and a prompt if they do not; questions about mental capacity and guidance on appropriate actions. In addition a prompt for contacting the LD nurse liaison team is included. The same document is audited monthly for completion of the clinical risk assessments on all patients. [Nursing Initial Assessment Document](#)

**Queen Elizabeth:** A recent re-assessment of the hospital environment in relation to meeting the needs of the disabled and the need to include low glare flooring for patients with autism is now part of the ongoing estates work plan.
Norfolk and Norwich:
- There is a rapid risk assessment tool in place which assesses the need for longer risk dependency assessment. The assessments identify specific care bundles and any additional support required. All individuals with a Learning Disability alert on the PAS system receive a rapid risk assessment by the admitting nurses on the wards or at pre admission appointments to support admission.

Rapid Risk Assessment for patients with Learning Disabilities and/or Autism
Senior Nurses

- A Carers partnership agreement and policy is in place to support safe admission.
- The trust also has a 1:1 Care of adult patient policy to ensure the hospital identifies the need for 1:1 bank nursing staff to reduce risks for patients with learning disabilities / other vulnerable patients.

James Paget: are also using the NNUH rapid risk assessment tool

Basildon and Thurrock: Has a learning disability specific Risk Dependency tool kit - this assessment can formulate the need for additional support for the patient.

Mid Essex: Dependency assessment & support tool is in place specifically for people with LD - the assessments tools can be downloaded from the Trust Intranet - LD clinical pages.

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<tr>
<th>2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration.</th>
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<tr>
<td>Luton and Dunstable: The Trusts Admission proforma has been recently redesigned and the one in use has reminders/prompting re learning disability cognitive assessment and also re nutrition risk assessment.</td>
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<tr>
<td>Norfolk and Norwich:</td>
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<tr>
<td>• Hospital SALT and Dietetic teams work closely with community Speech and Language Therapists (SALT) and Dietician to ensure there is good liaison to manage high risk patients.</td>
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<tr>
<td>• Education and training has been provided to all link practitioners to ensure better awareness and understanding in relation to meeting needs in this area.</td>
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<tr>
<td>Basildon and Thurrock: There are specialist staff on every ward who can carry out swallow assessment before referring to SALT. There are SALT Links to every ward.</td>
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<tr>
<td>Mid Essex: The purple communication resource folder distributed to each ward - has a selection of pictures - including food/drinks where communication is a barrier.</td>
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**Queen Elizabeth:** The Trust has provided pictorial menus on all wards which are printed on a pale yellow background with blue print to reduce glare for patients with autism.

**James Paget:** training in dysphagia recognition and the need to escalate has been given to mealtime assistants and to link practitioners.

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<thead>
<tr>
<th>2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments.</th>
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<tr>
<td><strong>Peterborough &amp; Stamford:</strong> Trust has an effective flagging and tracking system in place for people with a learning disability. There is excellent communication between the Trust, NHS Peterborough and Peterborough GPs so all Peterborough patients identified as having LD are on the Trust register. A protocol has been agreed with GPs regarding annual health checks and referrals to the hospital: <a href="#">GP Practice Step By Step Protocol - To Develop and Deliver Annual Health Checks for People with Learning Disabilities</a>.</td>
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<tr>
<td><strong>Queen Elizabeth:</strong> A letter has been sent to all referring GP practices in October 2011 advising them of the role of the LDLN and requesting that they proactively share information on all learning disability referrals.</td>
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<tr>
<td><strong>Luton and Dunstable:</strong> Pre-assessment pathways &amp; GP letters to identify people prior to admission have been discussed with colleagues in the community through links with GP Commissioning and the Partnership Board Sub Group. Consolidation of pre-assessment pathways is led by a hospital Anaesthetists and includes working GPs on admission information.</td>
</tr>
<tr>
<td><strong>James Paget:</strong> a flyer to GPs and a presentation to Clinical Commissioning Groups has highlighted the need for people with a learning disability / autism to be identified in referrals.</td>
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<tr>
<td>Caldicott agreement in place to share GP learning disability registers: James Paget; Bedford; West Herts; E&amp;N Herts; Ipswich; Basildon and Thurrock; Southend.</td>
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<tr>
<td>Caldicott agreement with local authority to share learning disability caseloads (the basis of GP registers): West Suffolk; Luton and Dunstable.</td>
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<tr>
<th>2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to all hospital staff.</th>
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<tr>
<td><strong>The University of East Anglia,</strong> having been commissioned by NHS Midlands and East, has published a Learning Disabilities and Autism Flexible Learning Package. This includes resources which can be used in formal training sessions, or in a 1:1 or small group learning session in the ward or department or ‘at the bedside’. The package offers continuing professional development credits, but can also be used by any professional, service user or family carer. The package is available here: <a href="http://www.uea.ac.uk/foh/mpe/learning-disabilities">http://www.uea.ac.uk/foh/mpe/learning-disabilities</a>.</td>
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West Herts; East & North Herts: E-learning package for safeguarding vulnerable adults is being implemented from October 2011. It will be accessible for all staff by June 2012.

Basildon and Thurrock:
• Have a training strategy including induction, Communication Matters Training Bi Yearly event; Board & Non Executive Training.
• Newly launched resource package: ‘From Board to Ward’. The package contains resources, best practice, documents and templates for staff to access and use. The pack has been shared across the east of England.

Colchester: Have developed learning disability champions amongst the pre-registration learners from the University of Essex and from Anglia Ruskin University. Two sessions have been completed so far and 8 champions identified.

Ipswich:
• There are 40 ward level Learning Disability/Autism Link professionals who receive extra training in Learning Disabilities issues.
• Adults with learning disabilities or autism and family carers were actively involved in developing the curriculum.
• A patient experience DVD forms part of the training for staff. It was developed by the Trust based upon feedback from a user and her sister following a poor experience as an in-patient.

Queen Elizabeth: Workshops and more advanced training sessions have been provided for the learning disability champions and these have included participation from family carers.

Norfolk and Norwich:
• All staff receive basic awareness LD/autism training on induction.
• Link practitioners have received extra training which is ongoing.
• People with a learning disability/autism and carers are actively involved in all training and curriculum development. We have developed a group of “expert patients” to help us with this.
• There is a comprehensive training plan.

James Paget:
• All staff receive basic awareness Learning Disability/Autism training at induction
• The Learning Disability/Autism Link Practitioners have received additional training
West Suffolk:
- At least two staff from every ward/clinical department have undertaken additional training in the needs of people with a learning disability. This was delivered over two days with work carried out in between.
- A learning disabilities module on the apprenticeship programme has been made mandatory, ensuring that this will be covered by all staff undertaking the apprenticeship scheme.
- A Learning Disabilities Awareness e-learning module has been developed for use across the Trust. This will be targeted initially at all nursing and ancillary staff, and rolled out within the next year.

Mid Essex:
- Two volunteers with learning disabilities work closely with the Liaison Nurse and are actively involved in developing/delivering training and audit to hospital staff. One has recently won an award for his work - “Volunteer of the Year 2011”.

3. Pathways

| 3.1 Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately. | Luton and Dunstable: Easy Read information is available on the Intranet about particular common procedures e.g. having blood taken and about common illnesses and this can be printed off during the appointment. |
| | Queen Elizabeth: There is an easy read appointment letter available for use when the person is known to have a learning disability. General correspondence from the Trust is designed to be read by individuals with a reading age of 11 years old. |
| | Norfolk and Norwich: Areas such as day procedure unit and radiology have already developed accessible information to support patients attending their departments. |

| 3.2 Adults with learning disabilities or autism attend A&E appropriately. | Queen Elizabeth: There is a multi-agency Frequent Attender’s Group in the Emergency Department that meets to discuss issues involving individual patients. Where appropriate, the LDLN is involved in supporting the development of a plan to re-direct the person to more appropriate services. |
| | Norfolk and Norwich: A&E has a system to record regular attendees with LD/autism and then link with the Liaison Nurse. |
| | Basildon and Thurrock: There is a clear training plan with A&E staff. |
### 3.3 Adults with learning disabilities or autism are discharged home in a safe and timely way.

**West Herts:** Pathways are in place and patients are fast tracked within A&E depending on the individual’s needs. The Health Liaison team have worked with learning disability care homes and developed a protocol on when to attend hospitals and access to other services, for example NHS Direct.

### 3.4 Women and partners with learning disabilities or autism have a clear pathway for use of maternity services.

**West Herts and East & North Herts:** Have an easy read discharge form for people with a learning disability as well as the professional who will be supporting the person.

**Easy Read Learning Disabilities Leaflet**

**Hinchingbrooke:** clear pathways are in place that make reasonable adjustments for the needs of parents to be with learning difficulties or autism.

**Addenbrookes:** Maternity services use a learning difficulty/disability screening tool. There is a Maternity Services Learning Disability flowchart.

**Colchester:** has Women with Learning Disabilities Maternity Services Guidelines which give advice on information giving for women with a learning disability accessing the service.

**Peterborough & Stamford:** Learning Disability Specialist Midwife in post and has a Learning Disability Maternity Pathway.

**Queen Elizabeth:** Women and partners with learning disability or autism are identified in early pregnancy and specific support is provided by the midwives for vulnerable women. Ante-natal classes specifically for women with learning disabilities are available.

**Basildon and Thurrock:** Has a Learning Disability Maternity pathway: *Care of a Patient with a Learning Disability in the Acute Hospital (Maternity).*

**James Paget:** Specialist midwives for vulnerable women are in place and will specifically work with women with learning disability / autism.
### 4. Involvement and representation of people with learning disability and their carers.

| 4.1 Adults with learning disabilities or autism and their family carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation. | **Ipswich:**  
- Patient experience quality outcomes are currently defined within CQUIN.  
- Adults with learning disabilities or autism and family carers are asked to participate in service evaluation. A feedback tool has been designed in ‘easy read’ format to specifically gather the views of people with a learning disability or autism, and carers/supporters: [Feedback Form](#).  
[Carer’s Feedback Form](#)  

**West Suffolk:** Patient experience interviews and surveys specifically for people with a learning disability and their carers have been carried out quarterly over the last year and an action plan developed to address the findings.

**Mid Essex:** Following discharge from hospital, a service evaluation sheet in accessible format is sent out to patients and family carers by the liaison nurse.

**West Herts, Colchester, and Norfolk and Norwich:** also undertake satisfaction surveys of people with a learning disability (see 5.3).

| 4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery. | **West Herts:**  
- Protocol in place for patients attending endoscopy as part of national bowel screening programme adhering to principles of MCA.  
- Sexual health DVD been developed to support patient with LD and autism attending services.  
- The Health Liaison Team employs an expert patient who has been supporting these developments and reporting back through local LD networks.

| 4.3 People with learning disabilities or autism are represented in the workforce. | **Norfolk and Norwich:**  
- The Trust runs an education employment programme (Project SEARCH) for people with learning disability/autism.  
- Reasonable adjustments have been made in the recruitment process.  
- 8 people with LD autism have been recruited from this programme and are in substantive jobs in the hospital  
- There is a system for ongoing support.  
- There are significant numbers of people with a learning disability/autism who work as volunteers in the Trust.
Queen Elizabeth:
• The Trust has people with learning disabilities and autism working in substantive posts e.g. Endoscopy Porter through the Project Search Programme.
• Reasonable adjustments are made in the recruitment process to facilitate easier employment such as using the employment record rather than a face to face interview. People recruited following participation in the Project Search programme are provided with ongoing support in their employment.

James Paget: 5 people have gained employment at the hospital through Project Search.

Addenbrookes: Provide work placements for people with learning disabilities some of whom have gone onto be employed in substantive posts. The Trust has a formal partnership Support into Employment Agreement with the Papworth Trust to formalise joint working arrangements.

Peterborough & Stamford: Volunteers with learning disabilities regularly act as hospital guides. The Trust employs people with learning disabilities and autism on substantive contracts

Mid Essex: Two people with a learning disability are volunteers within the Trust and co-facilitate training.

Southend: is working with the Skills for Health programme, resulting in 3 people with a learning disability being offered employment at the hospital.
5. Information for people with learning disability and their carers.

5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions.

**Bedford:** Two DVDs have been produced to provide accessible information about the environment and any specific procedures. One relates to emergency admissions and the other to elective admissions.

**Basildon and Thurrock:** A pre-admission booklet is used with the Day Unit to support patient understanding of what to bring with them.

5.2 All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.

**West Herts:**
- The Trust has produced a DVD for sexual health, been involved in the Purple folder DVD material, and produced a DVD ‘Through Barry’s eyes’.
- Cancer information is provided by Macmillan services in easy read format.

**Norfolk and Norwich:**
- Areas such as day procedure unit and radiology have developed accessible information to support patients attending their departments.

5.3 People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback.

**West Herts:** Health Facilitations team and Powher advocacy service undertake an ongoing audit to find out the views of patients with a learning disability regarding their hospital experience following discharge. This is linked to CQUIN targets.

**Colchester:** A hospital satisfaction survey for people with a learning disability is sent out annually to 20% of people with a learning disability who are known to have used hospital services in the previous year.

**Ipswich:** A feedback tool has been designed in ‘easy read’ format to specifically gather the views of people with a learning disability or autism and family carers/supporters: Feedback Form Carer’s Feedback Form

**Luton and Dunstable:**
- The Trust monitors complaints from adults with a learning disability or their carers picking up each individual case and reporting through the clinical operational board. Past complaints from families of adults with a learning disability have featured at Board seminar and within Board Quality Reports.

**Queen Elizabeth:** Learning Disability is now a flag on the Trust’s complaint database and will allow analysis of complaints according to whether the subject of the complaint had a learning disability.
Norfolk and Norwich:
- Complaints and feedback are regularly reviewed and monitored through the PALS report and equality and diversity meetings.
- Satisfaction/feedback surveys are conducted.

### 6. Keeping people safe

<table>
<thead>
<tr>
<th>6.1 The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism.</th>
<th>Ipswich: This group of patients are identified separately on the DATIX incident reporting system with an automatic trigger to the LD liaison nurse via e-mail.</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.2 The Trust demonstrates learning from other incidents involving people with learning disability or autism.</td>
<td>Queen Elizabeth: Electronic flags are in place within the incident reporting system.</td>
</tr>
<tr>
<td>Norfolk and Norwich: Patient safety walkabouts by the executive committee take place weekly across the hospital and issues related to safety of patients with LD have been highlighted and discussed by staff at some of these.</td>
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<tr>
<td>Bedford: The Director of Nursing conducts a weekly walk about of wards, with a particular interest in the care and treatment of people with a learning disability.</td>
<td>James Paget: All safeguarding and incident reports involving vulnerable adults are forwarded to the Deputy Director of Nursing for investigation. Where the incident involves someone with a learning disability / autism, the Liaison Nurse is involved in the investigation.</td>
</tr>
<tr>
<td>6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this</td>
<td>Ipswich:</td>
</tr>
<tr>
<td></td>
<td>- There is involvement guidance in place for user groups and other representatives on committees.</td>
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<td></td>
<td>- A DVD has been developed with a patient who has a learning disability and their carer. The carer attended a Trust Board meeting to discuss their experiences. Changes were made to practice. The DVD is now used extensively in training.</td>
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<td></td>
<td>Queen Elizabeth: The Trust now has 4 Foundation Trust members with a learning disability.</td>
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<td></td>
<td>Norfolk and Norwich: The top ten tips DVD was developed at the request of individuals with LD and fully incorporated their views.</td>
</tr>
<tr>
<td></td>
<td>West Herts; Colchester; Ipswich and Norfolk and Norwich: each undertake satisfaction surveys of people with a learning disability and (for Ipswich) family carers / supporters. See objective 5.3.</td>
</tr>
</tbody>
</table>

40
Appendix 3: A detailed review of the east of England acute Trust self assessments

Following is a review of the validated self assessments against each of the 23 objectives in the self assessment framework. The review sets out areas of achievement as well as concerns. This should be read in conjunction with Appendix 2 which sets out in more detail the examples of good practice described in the self assessments.

Please Note: the boxes in the Overview column show the number of validated RAG ratings for the 17 Acute Hospital Trusts.
### Top targets and objectives

<table>
<thead>
<tr>
<th>E of E rating</th>
<th>Overview of the Validated Self Assessments</th>
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</table>

#### 1. Leadership, management and strategy

1. Leadership, management and strategy

- 5 Trusts have a Non-Executive Director with a champion role for learning disability/autism, or for Vulnerable Adults.
- 15 Trusts have an Executive Director as lead on learning disability/autism.
- 10 Trust Boards have received reports on learning disability whilst 5 Trusts have a learning disability action plan.

Given the importance of leadership in driving forward improvements in relation to learning disability and autism, it is a concern that 2 Trusts have no Executive Director leadership for this work. Identifying a Non-Executive Director and a clinical lead to take a champion role is an effective way of bringing a broader leadership to this agenda.

- 12 Trusts have an electronic flagging system in place able to provide some reports on learning disability, although usually with further work needed to cover all Departments e.g. A&E and a full range of reports. 5 Trusts are developing a flagging system and cannot provide reports from their patient information system.

Without a flagging system in place across all hospital information systems, Trusts cannot reliably monitor the effectiveness of their strategy and plans. An important opportunity is also missed in supporting staff to recognise and plan for reasonable adjustments when a patient has a learning disability and/or autism.

Trusts are increasingly aware of the needs and risks for people with autism, but this will gather much more pace as more progress is made with local autism strategies.
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<th>Top targets and objectives</th>
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| 1.2 The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism. | ![E of E rating](image) | - 9 Trusts have a specific learning disability / autism policy some of which are summary policies which refer and signpost to other relevant policies.  
- The remaining 7 Trusts will be specifically considering the needs of people with learning disability / autism when reviewing key policies over the next review cycle.  
- 6 Trusts have a Policy for family carers (not only learning disability/autism)  
- One Trust (Addenbrookes) has a policy for the transfer of children with a learning disability to adult services. |
| 1.3 Partnership Working takes place at all levels within the organisation. | ![E of E rating](image) | - All Trusts are represented on their Learning Disability Partnership Board whilst most Trusts are engaged with their Adult Safeguarding Board.  
- One Trust (West Herts) has a Care Pathway Group for Children with Special Needs and also an End of Life Care Group, chaired by the Learning Disability Health Liaison Nurse with MacMillan Nurses attendance.  

Protocols with community learning disability teams: the self assessments have highlighted that the lack of any formal protocol about the respective roles and responsibilities of community learning disability teams and the Trust significantly hampers the ability to prepare people and make reasonable adjustments before admission and to ensure discharges are well planned and effective. Commissioners have a key role to play in ensuring these protocols are in place. At the time of the self assessments, one Trust (James Paget) had a draft protocol ready for agreement. No agreed protocols were in place. |
One Trust (Peterborough and Stamford) has a protocol agreed with GPs on referring people with a learning disability to hospital.

Few Trusts were engaged locally with work to plan and implement a local autism strategy at the time of the self assessment. This is key to effectively extending improvements in access and outcomes to adults with autism, with most improvement plans including this as an action.
### 2. Care standards, reasonable adjustments and service delivery

<table>
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<tr>
<th>Top targets and objectives</th>
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<tbody>
<tr>
<td><strong>2.1</strong> The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for adults with learning disabilities.</td>
<td></td>
<td>- 16 Trusts have a Learning Disability Liaison Nurse (3 have taken up post during and just after the validation process) and 1 Trust has a Disability Advisor.</td>
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<td>- 15 of these posts are substantive and full time (2 Trusts have more than 1 full time post). 1 post (West Suffolk) is part time and on a 1 year contract; 1 post (Princess Alexandra) is full time with consideration currently being given to the length of contract.</td>
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<td>- Most Liaison Nurses are employed by the Acute Trust, with some employed by the specialist Mental Health Trust and, in Hertfordshire, by Hertfordshire County Council as members of the community learning disability services.</td>
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<td>- 14 Trusts have Learning Disability/Autism link nurses/champions and 2 have Vulnerable Adult Link Nurses in wards and clinical settings. These link nurses range in numbers from a handful to 52. Some Trusts have agreed roles and responsibilities for these staff, others have more informal arrangements.</td>
</tr>
</tbody>
</table>

| **2.2** The Trusts’ plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disabilities or autism. |               | - 1 Trust (West Suffolk) has a flagging system which is able to provide reports on adults with a learning disability / autism from black and minority ethnic groups. |
5 Trusts have Public Sector Equality Duty action plans which specifically reference learning disability (but not necessarily autism).

2 Trusts have developed an audit tool for reasonable adjustments during and since the self assessment.

Trusts without a comprehensive flagging system found it difficult to evidence that they were able to identify everyone with a learning disability/autism using hospital services. This prevents them from undertaking and reporting on audits which include that whole group of people rather than those known to the Liaison Nurse.

This is particularly relevant to objectives 2.3 (fundamental care); 2.4 (risk); 2.5 (nutrition and hydration); 5.3 (complaints); 6.1 and 6.2 (serious incidents, deaths and safeguarding).

All Trusts aim to use Hospital Passports during the hospital stay. However, this is not embedded in practice in most Trusts, with a lack of consistency in clinical staff asking for the passport and passports not always transferring in case notes with the patient. In addition, many people have not been supported by community based services (health, social care or housing) to complete a Hospital Passport.

Hertfordshire has a well established and successful Purple Folder system which goes with the person whilst in the community and when in hospital.

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</table>
| 2.3 Adults with learning disabilities or autism receive high standards of fundamental care. | ![E of E rating](image) | - 5 Trusts have Public Sector Equality Duty action plans which specifically reference learning disability (but not necessarily autism).
- 2 Trusts have developed an audit tool for reasonable adjustments during and since the self assessment.

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Hertfordshire has a well established and successful Purple Folder system which goes with the person whilst in the community and when in hospital. |
Auditing fundamental care is a high priority for all Trusts, with frequent audits being undertaken for the full range of patients including people with a learning disability / autism. Most Trusts do not audit the fundamental care of people with a learning disability/autism as a specific group and are not able to report on this. This is a concern given the need for Trusts to satisfy themselves that reasonable adjustments are assessed and being made for this group of high risk patients.

2 hospitals (Luton and Dunstable and Addenbrookes) undertake specific audits of fundamental care for people with a learning disability, either by auditing the care of a group of people on a specific day, or ensuring that audits regularly include people with a learning disability and report specifically on their care. Audit teams have contributed enthusiastically to the development of these audit approaches.

An electronic flagging system is key to identifying everyone who should be included in audits of fundamental care.

- Risk assessment is a high priority for all hospital patients at all Trusts. However, most adults with a learning disability / autism will face areas of risk in hospital (some very significant) and will require reasonable adjustments to be made to address these. Trusts have taken slightly different approaches in this area.

- Some Trusts include questions in their initial nursing assessment document which identify if someone has a learning disability, their mental capacity, guidance on appropriate actions, and the person’s communication needs. This enables early identification of key risk issues for further risk assessments to then be undertaken.
A few Trusts use a Rapid Risk Assessment Tool when someone is identified as having a learning disability. Other Trusts use a risk and dependency assessment specifically for people with a learning disability when additional support needs are identified. These are usually completed by the Liaison Nurse.

The consistent and effective use of hospital passports also plays a key role in identifying and managing risks.

A consistent issue in the self assessments is whether Trusts are able to demonstrate and assure themselves that risks are assessed and reasonable adjustments made for all adults with a learning disability / autism. Most Trusts do not audit risk assessments and management plans for people with a learning disability/autism as a specific group and are not able to report on this. Similarly to the areas of fundamental care and nutrition/hydration, this is a concern.

1 Trust (Luton and Dunstable) identified in its self assessment that it audits that risk assessments for people with a learning disability are effectively undertaken during the nursing initial assessment.

Audits of risk can be undertaken either by auditing the care of a group of people with a learning disability/autism on a specific day, or ensuring that audits already being undertaken include people and report specifically on their care. An electronic flagging system is key to identifying everyone who should be included in audits of risk.
Trusts have incorporated the National Patient Safety Agency guidance on safe swallow for people with learning disability into their safe swallow guidance. 4 Trusts state that they have safe swallow guidance developed locally. Dysphagia (difficulties swallowing) is a serious problem for some people with a learning disability and poses very high risks including death if not managed appropriately. It is a real concern that not all Trusts have specific guidance in this area (national or local). The RAG rating for this objective may be over optimistic.

- Many Trusts identify special dietary and eating needs through coloured jug and tray systems. Easy read menus are widely used and some Trusts see their ward housekeeper as having a key role in ensuring appropriate arrangements are in place.

9 Trusts now have Caldicott agreements to populate their patient information systems either from GP learning disability registers or with people who are known to adult social care (the basis of GP registers). This enables most people, but not everyone, with a learning disability to be identified by the hospital at the earliest point of referral. These registers include people who have a learning disability and autism, but not people who have autism alone.

- 1 Trust has a protocol agreed with GPs to signal that someone has a learning disability when they refer to the hospital.

### Top targets and objectives

| 2.5 | The Trust employs a registered healthcare practitioner for adults with learning disabilities or autism (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for adults with learning disabilities. |
| E of E rating | ![Orange](image) |
| Overview of the Validated Self Assessments | ![Green](image) |

- 2 Trusts have incorporated the National Patient Safety Agency guidance on safe swallow for people with learning disability into their safe swallow guidance.
- 4 Trusts state that they have safe swallow guidance developed locally.

### Overview of the Validated Self Assessments

| 2.6 | Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments. |
| E of E rating | ![Orange](image) |
| Overview of the Validated Self Assessments | ![Green](image) |

- 9 Trusts now have Caldicott agreements to populate their patient information systems either from GP learning disability registers or with people who are known to adult social care (the basis of GP registers). This enables most people, but not everyone, with a learning disability to be identified by the hospital at the earliest point of referral. These registers include people who have a learning disability and autism, but not people who have autism alone.

- 1 Trust has a protocol agreed with GPs to signal that someone has a learning disability when they refer to the hospital.
### Top targets and objectives

#### 2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to all hospital staff.

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<tbody>
<tr>
<td></td>
<td>A protocol with community learning disability teams should include the identification of the person to the hospital if known to the team prior to admission to significantly support this objective.</td>
</tr>
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</table>

- Most Trusts rely on their Learning Disability Liaison Nurse to deliver training, often with up to half of their time being spent in this area. The average rating is low because of the difficulty in delivering training to the full range of hospital staff at induction and through updates.

The recently launched east of England Learning Disabilities and Autism Flexible Learning Package makes training and information resources very widely available across the region and with continuing professional development credits attached. Basildon and Thurrock Hospital have recently launched a resource pack: ‘From Board to Ward’, also shared across the east of England.

- The Learning Disability link nurses / champions often have a key role in supporting colleagues to access information and resources.

- 8 Trusts have Learning Disability Resource files on wards, including guidance on the care of people with a learning disability and communication aids.

- 10 Trusts have learning disability resources on the Trust intranet, many linked through to other nationally available resources e.g. the easy health web site.

- 3 Trusts involve self advocates and family carers in delivering training to staff.
Most Trusts have said that their letters are not complex and use simple language. However, very few use pictures or symbols. Where the Liaison Nurse knows of the referral, they may put letters into easy read.

Trusts without a learning disability/autism flag on their patient information system are not able to identify people early in the pathway who are likely to need easy read letters and information.

A protocol with community learning disability teams should include, for outpatient appointments, preparation of people known to the team and identifying reasonable adjustments to the hospital.

7 Trusts are able to identify people who repeatedly attend A&E, usually as part of a system to identify any patient who is frequently attending.

Most if not all the learning disability liaison nurses have contact with their community learning disability teams to discuss people attending A&E where these people are identified. However, this is usually on an informal basis without any agreement or protocol of roles and responsibilities.

<table>
<thead>
<tr>
<th>3.1 Adults with learning disabilities or autism attend outpatient appointments investigations appropriately</th>
<th>E of E rating</th>
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<tr>
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<table>
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<tr>
<th>3.2 Adults with learning disabilities or autism attend A&amp;E appropriately</th>
<th>E of E rating</th>
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<tr>
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<td>7 Trusts are able to identify people who repeatedly attend A&amp;E, usually as part of a system to identify any patient who is frequently attending.</td>
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Most if not all the learning disability liaison nurses have contact with their community learning disability teams to discuss people attending A&E where these people are identified. However, this is usually on an informal basis without any agreement or protocol of roles and responsibilities.
All Trusts state that they start discharge planning on admission as part of their overall policy. Where someone is known to have a learning disability the Liaison Nurse is usually involved to varying degrees. All Trusts state that complex discharge plans are developed on a multi-disciplinary basis.

It is less clear from some Trusts how routinely the community learning disability team is involved in discharge planning. A protocol with community learning disability teams should include appropriate and respective roles and responsibilities in planning for discharge.

Data on readmissions and delayed discharges is monitored by all Trusts. Without a learning disability/autism flag on patient information systems it is not possible for Trusts to monitor and understand issues and costs around extended lengths of stay for this group of people.

No Trusts yet compare data for extended length of stay for people with a learning disability against data for the whole patient population.

Some Trusts have developed specific approaches for women with a learning disability or ‘vulnerable’ women or in relation to safeguarding.

7 Trusts have a learning disability / vulnerable women / safeguarding pathway whilst 6 Trusts have a learning disability / vulnerable women or safeguarding lead midwife.

<table>
<thead>
<tr>
<th>Top targets and objectives</th>
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<tbody>
<tr>
<td>3.3 Adults with learning disabilities or autism are discharged home in a safe and timely way</td>
<td><img src="image" alt="E of E rating 3.3" /></td>
<td><img src="image" alt="Overview of the Validated Self Assessments 3.3" /></td>
</tr>
<tr>
<td>3.4 Women and partners with learning disabilities or autism have a clear pathway for use of maternity services</td>
<td><img src="image" alt="E of E rating 3.4" /></td>
<td><img src="image" alt="Overview of the Validated Self Assessments 3.4" /></td>
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There is a real tension between supporting the mother through the birth and safeguarding concerns for her baby. There are concerning indications that safeguarding processes are used in some Trusts whenever a mother with a learning disability is identified rather than when specific safeguarding issues are identified.

### 4. Involvement and representation of people with learning disability and their carers

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<td><strong>4.1</strong> Adults with A/G learning disabilities or autism and their family carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation</td>
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- 12 Trusts have a specifically Learning Disability forum for developing and evaluating services. These usually have a wide membership including self advocates, family carers, advocates as well as professionals. A few are chaired by a family carer and/or a self advocate. The other 5 Trusts have involved self advocates and family carers in broader patient groups e.g. Patient Equality and Diversity Groups.

These groups will include people with autism who also have a learning disability. No Trust has engaged with people specifically because of their autism.

1 Trust does not have a forum for people with a learning disability/autism.

- Most of these fora have been involved in specific, valuable service developments e.g. easy read information, signage and some in finding out how services are doing.
However, few Trusts have had a learning disability action plan (see 1.1) up to now. This has significantly limited these groups in their ability to be involved effectively and comprehensively in the planning and evaluation of services e.g. through regular reports on progress and agreeing priorities. Nor have fora received reports to enable them to judge how well the Trust is performing e.g. complaints; clinical audit outcomes.

- The agreement of these acute hospital self assessments and improvement plans has enabled these fora, and Learning Disability Partnership Boards, to be more effectively engaged with and by Trusts.

Implementation and regular reporting of the Learning Disability/Autism Dashboard of Improvement, Quality and Efficiency Measures recommended in Chapter 6 to Learning Disability/Autism fora (or other groups) will provide a firm basis for people’s involvement in planning and evaluation of services.

4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery

- Planning and co-production is regularly undertaken when someone is known to the Learning Disability Liaison Nurse, or is identified as having a learning disability early in the referral. The use of hospital passports and, in Hertfordshire the purple folder system, greatly enhances people’s involvement in planning. However, Trusts without a learning disability/autism flag on their patient information system are not able to comprehensively identify people with a learning disability or autism at referral to enable this involvement.

- 7 Trusts have a Family Carers policy (not necessarily learning disability / autism specific) which includes the involvement of carers in planning care through the pathway.
Some Trusts identify a named person in the department / ward a person will be using. Where someone has complex needs, the named person is often the Learning Disability Liaison Nurse.

A protocol with community learning disability teams should include enabling the involvement of service users and family carers involvement in planning for admission and discharge.

<table>
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| 4.3 People with learning disabilities or autism are represented in the workforce. | ![E of E rating](image) | - The majority of Trusts are unable to identify whether any employees have a learning disability or autism. Some employees are not willing to have this recorded.  

- Project Search (Norfolk and Norwich, Queen Elizabeth and James Paget) has clearly had a sustained impact on the Trusts’ employment of people with a learning disability or autism. Some other Trusts have made progress through formal agreements with supported employment services and by making adjustments to recruitment processes.

Generally, few acute Trusts are taking positive steps to employ people with a learning disability or autism despite the positive benefits that accrue to the organisation and the individual. |
### 5. Information for people with learning disability and their carers

<table>
<thead>
<tr>
<th>Top targets and objectives</th>
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<th>Overview of the Validated Self Assessments</th>
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| 5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions. | ![E of E rating](image) | - Several Trusts have developed DVDs as well as easy read information, usually available on-line. Links to other web sites e.g. Easy Health is also often provided on Trust web sites.  
- Where people are already known to the Trust, and particularly the liaison nurse, they are likely to receive appropriate information. Trusts without a learning disability/autism flag on their patient information system are not able to identify people early in the referral process who are likely to need easy read information etc.  

A protocol with community learning disability teams should include enabling people to access appropriate information, particularly where this is only available electronically. |
| 5.2 All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers. | ![E of E rating](image) | - 11 Trusts make easy read information available for staff to use through the Trust web site whilst 8 Trusts specifically mention that ward / department resource packs include easy read information. However, there are very few with a comprehensive range of accessible information. A few Trusts have developed DVDs to provide information.  
- All Trusts have learning disability or Vulnerable Adult link nurses / champions who are able to support the use of accessible information. Including this in the agreed roles and responsibilities for these staff will be helpful.  
- Some Trusts have reader panels including people with a learning disability. |
5.3 People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback.

- 14 Trusts have easy read / accessible complaints information.
- 6 Trusts are able to provide information on the number of complaints by people with a learning disability (but not autism). No Trusts yet compare the rate of complaints by people with a learning disability against the general rate of complaints received by the Trust.
- Several Trusts have a representative of their complaints team as a member of the learning disability forum, a key place for complaints teams to understand some of the issues facing people but which do not result in a formal complaint.
- A small number of Trusts have developed systems to gain feedback from people with a learning disability after discharge as a further way of learning about patient experience.

6. Keeping people safe

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<td>6.1 The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism.</td>
<td></td>
<td>- Trusts are generally very confident that their procedures for identifying and investigating serious incidents, near misses and deaths are of a very high standard for all patients, including people with a learning disability / autism and that learning is shared across the Trust.</td>
</tr>
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</table>
|                            |              | **• 2 Trusts have learning disability flags on their incident reporting system. For one of these Trusts, this generates an immediate e-mail to the Liaison Nurse.**  
Please see 6.2 commentary for associated concerns about performance in this area. |

**6.2** The Trust demonstrates learning from other incidents involving people with learning disability or autism.

- **All Trusts** report having incident reporting systems in place with clear pathways. Many have regular internal Safeguarding Steering Group meetings (or equivalent) alongside meetings with their safeguarding partners, particularly PCTs and local authorities.

- **A few Trusts** have incident reporting systems which are able to identify incidents involving people with learning disability or autism including safeguarding alerts. An electronic LD/Autism flagging system will greatly support this as would the inclusion of learning disability / autism on Trust Safeguarding of Vulnerable Adults and incident reporting documentation.

- **No Trust** is collating and analysing incidents involving concerns about the care and treatment of people with a learning disability or autism, or on safeguarding alerts.

An area of concern here (and linked to 6.1) is that serious and untoward deaths or incidents, near misses and safeguarding concerns involving people with a learning disability or autism may be under reported. Although Trusts are confident about their general systems for reporting on serious incidents and safeguarding, it is very possible that where people with a learning disability or autism are involved the staff reporting serious incidents and safeguarding incidents and those investigating them may not be recognising the impact and serious outcomes potentially caused by diagnostic overshadowing (which itself is often unacknowledged) and not making reasonable adjustments.
Training and education in this area for all potential reporters and for investigators of serious and untoward deaths or incidents, near misses and safeguarding concerns is critical to addressing this.

Better monitoring and scrutiny is also important through the collation and provision of reports to form part of the Learning Disability/Autism Dashboard for Trust Boards, Learning Disability Trust fora and Learning Disability Partnership Boards.

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| 6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this. | ![E of E rating chart] | **Training and education in this area for all potential reporters and for investigators of serious and untoward deaths or incidents, near misses and safeguarding concerns is critical to addressing this.**

Better monitoring and scrutiny is also important through the collation and provision of reports to form part of the Learning Disability/Autism Dashboard for Trust Boards, Learning Disability Trust fora and Learning Disability Partnership Boards.

- 5 Trusts undertake patient experience surveys specifically with adults with a learning disability and all Trusts have established ways of listening to people with a learning disability or autism and their family carers through a learning disability or patient experience group.

- There is also evidence of specific improvements to services as a result of feedback. Several Trusts have developed DVDs explaining the patient’s experience and how things should be done differently in that particular Trust for use in training and staff development.

- 1 Trust has 4 Foundation Trust members with a learning disability
Appendix 4: An analysis of the expected impact of improvement plans on the 2014 RAG ratings for six Trusts

Six Trusts have provided information on the RAG rating their improvement plans and are expected to deliver by 2014. Currently, 15 objectives are rated Amber and below on an aggregated east of England basis. The current and expected aggregated RAG ratings for the 6 Trusts in 2014 for the 15 objectives is shown below.

Also shown is the current east of England position, showing that these six Trusts have a similar or slightly worse aggregate rating as the overall position.

The expected position in 2014 is that the ratings of all these objectives will move to Amber/Green or Green, making this the position for all 23 objectives.

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<tr>
<td>2.2 The Trusts’ plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disabilities or autism.</td>
<td>![Orange]</td>
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<td>2.3 Adults with learning disabilities or autism receive high standards of fundamental care.</td>
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<tr>
<td>2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.</td>
<td>![Orange]</td>
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<tr>
<td>2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration.</td>
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</tr>
<tr>
<td>2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments.</td>
<td>![Orange]</td>
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</table>
2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to all hospital staff.

3.1 Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately.

3.2 Adults with learning disabilities or autism attend A&E appropriately.

3.4 Women and partners with learning disabilities or autism have a clear pathway for use of maternity services.

4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery.

4.3 People with learning disabilities or autism are represented in the workforce.

5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions.

5.2 All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.

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6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this.
Se desiderate ricevere informazioni in un'altra lingua o in un altro formato, siete pregati di chiedere.

Jeżeli chcieliby Państwo uzyskać informacje w innym języku lub w innym formacie, prosimy dać nam znać.

Se desea obtener información noutro idioma ou formato, diga-nos.

Türkçe bilgi almak istiyorsanız, bize başvurabilirsiniz.

如欲索取以另一语文印制或另一格式制作的资料，请与我们联系。