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Parents experiences of wheelchair services East of England - Oct 2010

These slides show the results of a survey carried out by NHS East of England Strategic Health Authority working with Contact a Family and parent carer forums across the East of England as part of their 2010/11 East of England Children and Equipment Wheelchair Project

The project then went on to write key recommendations for delivering an effective wheelchair service

If you want a copy of the questionnaire sent out please contact Sheila.Davies@cafamily.org.uk

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Background

Government Office East

Commissioned by DH to carry out review of children's equipment and related service
Approached Contact a Family for parent input

Contact a Family

Working with Together for Disabled Children (TDC) to support establishment of parent forums through Aiming High for Disabled Children
Facilitating regional networks of parent forums – including in the East of England
Agreed to use network to assist in designing survey and distribute survey to families

Aim: Improve outcomes for children with disabilities in the East region

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What we discovered

Family Voice - Southend

Had already worked with their PCT to design service (more about this later)

Norfolk

Already consulting with families on this issue locally –this will now be input to GO East (avoiding duplication of consultations)

Other local authority areas

Surveys sent out to families, distributed through forums

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Wheelchair service - Limited Choice

Frequently there was a limited choice of wheelchairs that did not meet child's or carers needs

"Too heavy and awkward and affected carer's back. Didn't meet child's health needs"

'"problem with footplates,. daughters feet do not sit on them, very bouncy/uncomfortable ride/difficult to turn in small space "

"only one option available -. asked about chairs that go up and down and have sprung back but told these were not provided."

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Wheelchair service: Complex needs

Service needs to be more flexible to individual needs & circumstance

- Difficult to get electric wheelchair, and different eligibility criteria applied across areas
- Difficult getting equipment if family living in one catchment area with child attending school in another as there are two agencies to go through
- Difficult for under 3 needing pram/chair to carry also medical equipment

Some parents had to buy their own equipment or approach charity to help fund one. These do not get regularly reviewed and families have to pay for repairs

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Wheelchair service waiting times

Varied enormously from 1 to 3 months to 2 years! Sometimes long wait for assessment and then another for equipment.

"Referral to wheelchair service wait is very long. Relatively short this time after child tipped chair over because it is too small - have had it 5 years

"referral easy but getting an appointment took over 6 months"

"first to get referred then any follow ups/reviews can take up to 2 years plus for an outdoor electric wheelchair"

"chair-took 18 months from referral and then it was wrong size "

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. Wheelchair Service: Information

Lack of information provided about many aspects of the service

“took voucher and left to order buggy - no support”

“do not know who to contact and the wheelchair service never contacts us once they give a wheelchair, even after years of use”

“Was not given opportunity to buy what we needed in cooperation with this service i.e. part funding or service contact”

“Not given proper info about chairs on the market, limited range available “

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Wheelchair service -reviews

Some children got regular reviews, but over half the children did not - this has impact on health and safety

"OT regularly checks during therapy sessions"

"only review when parents rings to request one -long wait for review date" .

"had to ask as not automatic he is now 6 does not fit in pushchair-however no follow up"

"is by physio but after referral to wheelchair service wait is very long. Relatively short this time after child tipped chair over because it is too small - have had it 5 years"

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Other Equipment

Some getting a good service

"Hoist and bath chair required and received "

"well supported at school and at home"

others not

"long wait for child's shower chair"

"chair-took 18 months from referral and then it was wrong size, bath seat wrong size, table took 18 months and too small, sats monitor took 3 years until they gave one that was suitable"

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What did families like?

Families appreciative of staff and felt they were under resourced

"staff and skills in wheelchair and equipment service of highest calibre"

Therapists are helpful and nice and try on your behalf

LA OT totally over stretched

repair service happy to attend home/school - quick to attend - staff friendly and approachable

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Meanwhile in Southend

Had a poor service, but not anymore

1. PCT and parents forum worked together to draw up service specification for wheelchair service
2. Service now outsourced to voluntary sector specialist
3. Family's say they are delighted with the new service
4. Parents encouraged to feedback any problems with service to forum
5. When this has occurred (very rarely) the forum contacts the PCT and problem has been quickly resolved
6. This assists PCT in monitoring outsourced service, and means parents do not have to go through costly and time consuming complaints procedures, something parents are usually reluctant to do

Appendix 1

Equipment and Wheelchair Services: Key Features of Effective Services

Author :
Bob Dawson
Project Lead
Enable East

March 2011

NHS
East of England

Children's Disability Equipment & Wheelchair project

1. Introduction

This project has been able to draw on the expertise and experience of parents, carers and users of service, service providers, therapists, commissioners and experts in the field of equipment provision and the associated information systems that support that provision. A guiding principle of the project is that every effort should be made to address health inequalities and achieve more regional equity in this important area of service and as one parent put it, establish services that are “dynamic, responsive and child centred”.

In broad terms the stakeholders have identified the importance of well organised arrangements for service user need assessment, care planning and review and correspondingly effective arrangements for the timely provision of appropriate equipment and wheelchair facilities. The following three sections aim to synthesize the key features of services that make a difference and should be captured within service specifications and related commissioning documentation. The first section refers to the core expectations that parents and carers have identified as being crucial to meeting their children’s needs and those of the primary carers. These expectations cut across the processes that are in place for decision making, applying eligibility criteria, assessment, provision and after-care arrangements. The second section builds upon this parent and carer statement of expectation to describe the key elements of effective equipment and wheelchair service provision as derived from the fieldwork, the parent and carer survey material and national guidance. The final section is aimed at commissioners and seeks to describe the key benchmarks that should underpin the commissioning of the assessment/provision pathway. Inevitably and appropriately there are strong interrelationships between all three sections.

A. Parent and carer expectations

This is effectively a seven point charter that could be signed up to by appropriate provider and commissioning organisations as it refers to commissioner determined decision making processes and criteria, as well as provider behaviours. Also key to the effective provision is the joined up working between provider agencies who all form part of the pathway for children and young people

The seven points are as follows:
Parents and carers can expect:

i) Timeliness
Assessments, provision, reviews and repairs to equipment to be undertaken in a timely way in accordance with the needs of their child or young person. These timescales will be made clear to families at the beginning of their involvement with the services and assessments will take into account their needs in the context of the wider family and environment.

ii) Transparency

Clear criteria for what equipment and services are available to them. These will be made available at the beginning of the process, and updated as required. There will be clear and understandable pathways of decision-making with no unnecessary delays, and written explanations will be provided to parents if requests for equipment are turned down because they do not meet criteria.

iii) Customer Care

A good service e.g. when equipment is delivered there is a warning of its arrival, it is fitted, and parents and carers are shown how to use and care for the equipment. There is a choice as to where this happens - at home/school or the wheelchair centre etc. Product manuals are provided and there are easy ways to contact the service if there are problems or difficulties with the equipment or if there are needs for repairs or replacements.

iv) Communication

To be kept informed of progress. If they make a complaint or have a concern about the service they are being given, they will get a speedy response with clear written answers and the actions being taken to resolve the problem.

v) Information

To be given helpful information, especially when they are not supplied with equipment by the service. They will be given information about local and national voluntary sector groups for advice and guidance, sign-posting to local or national charities who provide grants for specialist equipment, support for applications, and information and guidance re suitable equipment for the child's needs.

vi) Partnership and Participation

To be working in partnership with services. Parents and carers and where possible their children, will have their voices heard in the selection of any particular piece of equipment.

vii) Feedback and Involvement

To be asked for feedback by the services that provide the equipment and the assessments etc. This information will be used to monitor the services and inform the way the services are developed. Services and those who commission them, will engage with parents, carers, children, and young people in the area when planning or reviewing services.

2. Provider services: Arrangements for Effective Delivery

a) Needs Assessment services

A clear and simple pathway that includes:

- Criteria for entry onto the pathway that addresses issues of clinical need, social care, recreation, access to the educational curriculum
- Powered wheelchair criteria published

- Process / criteria for supply of wheelchairs/equipment to multiple settings (e.g. divorced parents) is published
- Clear entry to the pathway, preferably through a single point of contact
- Holistic, competent assessment and care planning by appropriately trained paediatric therapists carried out within nationally agreed timescales
- Family impact assessment undertaken as part of the assessment for equipment and wheelchairs
- Partnership working between agencies to ensure a joined up approach to equipment / wheelchair provision e.g., housing services (Disabled Facilities Grants etc), prosthetics and orthotics departments, education and social care, communication aids and other assistive technologies
- Multi agency lead professional/key worker arrangements are in place and operational, providing a first port of call for parents and carers
- Clear practice guidelines for therapists and other assessors / prescribers to ensure consistency of approach, clinical governance and effectiveness
- A dedicated equipment/wheelchair plan is produced that is a companion document to the care plan. This plan will describe the review frequency, with an emphasis of responsiveness to need.
- Process to be in place for addressing user need when service user moves out of area, or is in an educational or residential setting out of area.
- Process to be in place to ensure that equipment and wheelchairs follow the service user into adult services such as a further education college.
- Equipment and wheelchair needs are clearly part of transition planning arrangements
- Pathway compliance is routinely audited and evidenced and includes feedback from parents/ carers and children / young people

b) Equipment and Wheelchair providers:

- Are commissioned where possible to deliver a comprehensive and integrated service to health, education/schools and social care, utilising partnership funding flexibilities where appropriate
- Meet nationally agreed targets for assessment and delivery.
- Build in periodic systematic reviews of the equipment and wheelchairs provided.
- Deliver a customer focussed service that strives to provide time slots for delivery and collection, ensures customer satisfaction through skilled and efficient assembly, installation maintenance, repair and call out arrangements and provides relevant written guidance.
- Have a rapid response care pathway in place for children and young people who are experiencing discomfort in their wheelchair/seating/equipment and who may be receiving sub-optimal alternative care to compensate for the lack of suitable facilities.

- Equipment provided needs to take into account the specific clinical needs of children and young people who are growing and changing often rapidly but may still require equipment to be as robust as adult provision
- Endeavour to ensure that equipment needs identified as part of an end of life care plan are prioritised and care is taken to ensure that there is effective communication with community nursing teams throughout this critical period
- Have qualified paediatric therapists and paediatric technicians as part of the staff team
- Review catalogue composition and preferred specials with the assistance and advice from a regionally constituted clinical engagement panel.
- Secure year on year improvements in the volume of recycled specials and ensure that there are robust authorisation mechanisms that default to returned specials prior to ordering a new item
- To contribute, when established, to regional equipment and wheelchair re-selling initiatives to maximise the use of valued re-cycled equipment
- Enable, where practicable, trialling of equipment and wheelchairs to maximise user satisfaction
- Specify and invest in computerised stock systems that effectively track and monitor stock movement and generate a range of reports that alert commissioners and providers to trends in demand, utilisation of stock, new and recycled
- Demonstrate a multi-faceted approach to getting feedback on service performance and involvement in service development by parents, carers and users, including their engagement on advisory boards

c) Commissioning Actions

- Through collaborative action between health, social care, special educational needs commissioners, work towards a comprehensive assessment of local equipment and wheelchair needs across all key settings; health, schools, social care, for inclusion in the Joint Strategic Needs Assessment that will inform the Joint Health and Well-being Strategy and GP Consortia commissioning plans.
- Explore joint commissioning arrangements, utilising existing partnership funding flexibilities
- Produce transparent decision making process, with timescales, for high cost low volume items.
- Build up service specifications and performance and outcome measures that reflect the key features of good practice described in sections 1 and 2 above.
- Continue to support and develop parent, carer, and user involvement to inform evaluation of service performance and contribute to service development. To ensure effective links made with the new local HealthWatch services

- In collaboration with parent carer user forums and clinicians, identify and promote reliable sources of information on equipment and wheelchair innovations such as Whizz Kidz and the Disabled Living Foundation.
- Explore and cost out leasing options and compare with more traditional forms of provision
- Build on existing models of collaborative procurement to secure greater economies of scale.
- Exploit opportunities for utilising the potential of personalised budgets within health and social care as the process gathers pace.
- Work with relevant third sector organisations to ensure that parents and carers have informed choices and receive effective support especially when equipment provision is not available from the services.

East of England Learning Disability QIPP

Improving Acute Hospital Patient Pathways for Adults with a Learning Disability and Adults with Autism

April 2011

Foreword

I am very proud to be asked to write a few words as a forward to this document. I know many people with learning difficulties, including myself, who have not had good care from Health professionals. If all health staff have a commitment to putting this document into practice I would be very, very happy.

Please don't forget these gold standard pathways should not be viewed as a 'nice thing to do' but as a 'must do' to make sure people with learning difficulties and people with autism get their rights to good health care.

Richard Blake
Co-chair, East of England Learning Disability Programme Board

This document gets an immediate welcome from me as a family carer. This should make a real difference to my son's experience of hospital. The work has involved families, self advocates and practitioners from the outset. The guidance is practical and achievable.

What does it do? It embeds the principle - nothing about us without us. At its heart is the recommendation for a clear journey (pathway) through the hospital experience, putting the individual needs of adults with a learning disability or autism at the beginning, middle and end.

Who does it? Everyone - Chief Executive - yes, all the doctors - yes, all the nurses - yes, all the receptionists – yes. Everyone.

How? The core strengths of this document are the practical recommendations and guidance for a gold standard pathway, training, governance and monitoring, and the role of the Learning Disability Liaison Nurses. There are also lots of examples of good practice. The Liaison Nurses are fantastic, but please do not expect one nurse to do it all.

This is about creating a whole inclusive approach across each hospital, raising the awareness and skill of everyone and expecting good values and attitudes from all. The journey to improve acute hospital services for adults with a learning disability or autism began with the involvement of self advocates and family carers. It needs to continue in that spirit of co-production and partnership.

Helen Daly
Co-chair, East of England Learning Disability Programme Board

NHS East of England

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1. INTRODUCTION

We know through recent national reports, from clinical evidence and feedback from self advocates and family carers that people with a learning disability and people with autism have greater health problems than the general population. They can also have unequal access to health services, often through a lack of reasonable adjustments to meet their needs The NHS in the east of England has been particularly committed to addressing these issues over the last few years.

In 2009, 20010 and 2011 PCTs in the region have undertaken self assessments of how well their local health system is meeting the needs of people with a learning disability. The Vision for Better Health and Well Being for People with a Learning Disability and their Families 2011-21 will be published in April 2011 with a real focus on mainstream health services better meeting the health needs of people with a learning disability and those with autism so that equality of access and of health outcomes are achieved. Acute hospital services are a particular focus.

There have been improvements in acute hospitals in the east of England in the services they provide to adults with a learning disability and adults with autism, illustrated by the increase in the number of hospitals with learning disability liaison nurses in post. Out of 17 acute hospitals, eight had learning disability liaison nurses in post in April 2010, six have created and appointed to these posts in 2010/11. Three hospitals do not yet have these posts in place.

This report and its accompanying materials are intended to support acute hospitals, commissioners and Learning Disability Partnership Boards in the east of England to continue to improve all the acute hospital services provided for adults with a learning disability and adults with autism. For the purposes of this report, this means people aged 18+. The report includes the following:

1. High level pathways for Acute Hospital in-patient, out-patient and accident and emergency services for adults with a learning disability and adults with autism.
2. Guidance for more effective alert and information systems
3. A Quality Assurance Framework and models for self assessment and an Improvement Plan
4. A framework for workforce development
5. A model role and reporting structure for Learning Disability Liaison Nurses
6. Recommended protocols and joint agreements
7. An index of good practice in the east of England
8. Indicative levels of activity and possible savings

The report and materials have been developed with significant contributions from across the east of England. The Project Board and organisations which have contributed are detailed in Appendix 1.

By using the frameworks, tools and materials made available, acute hospitals, commissioners and Learning Disability Partnership Boards will be able to have confidence that they are improving the quality of services to people; introducing innovative practices; increasing productivity; and increasingly preventing people having health outcomes which are worse than those for comparable groups in the general population.

2. EXECUTIVE SUMMARY

The deaths of six people with a learning disability whilst in the care of the NHS led to the publication of The Michael report 'Healthcare for All' (2008) and the Joint Ombudsmen's Report: Six Lives (2009). Both reports revealed significant and, at time, shocking deficits in the healthcare people with a learning disability receive. A large part of the care for these six people was provided by acute hospitals.

The Department of Health's Six Lives Progress report (October 2010) reports that *'the ability of acute hospitals to provide a consistently good service to people with a learning disability continues to be an area of concern, particularly for those with the most complex needs'* (page 32). Feedback from people with a learning disability and their family carers and through the 2010 Learning Disability Health Self Assessments undertaken by each PCT in the east of England indicate that this is an accurate description of the situation in this region.

The current Mid- Staffordshire NHS Foundation Trust Public Enquiry is focussed on the role of commissioning, supervisory and regulatory organisations in relation to the Trust, making it clear that a whole system approach is needed within local health systems to ensure that acute hospitals are delivering improved care and outcomes for adults with a learning disability and adults with autism.

The 2011/12 Operating Framework includes commitments to improve the health of people with a learning disability and/or autism. Specifically it commits the NHS to:

- Maintaining momentum in improving care and outcomes for people with learning disabilities, in the light of the *"Six Lives" Progress Report*
- Ensuring staff are trained to make reasonable adjustments, communicate effectively and follow the *Mental Capacity Act (2005) Code of Practice* to ensure full compliance with the law

This QIPP project provides acute hospital Trusts, Commissioners and Learning Disability Partnership Boards with a number of frameworks and tools to improve acute hospital patient pathways for adults with a learning disability and adults with autism. Used over a period of time, these will enable Trusts and their partners to:

- Improve health outcomes
- Achieve cost savings and efficiencies
- Deliver greater consistency of service delivery within Trusts and across the east of England
- Reduce patient and corporate risks

The frameworks and tools provided are:

1. **High level Patient Pathways** for adults with a learning disability and adults with autism using elective and accident and emergency services (Chapters 3 and 4).

   These Pathways are for local development to meet the specific characteristics of each health system. It is key that these pathways are agreed as part of clinical governance

and known to all acute hospital staff, GP's, ambulance staff and specialist learning disability services.

2. **Indicative levels of activity and possible savings** (Chapter 5).

   Cost savings are available through the implementation of efficient and effective pathways; improved staff skills, knowledge and attitudes; sufficient learning disability liaison nurse capacity; achieving key protocols and joint agreements. However, the lack of comprehensive, consistent activity and cost data about the use made of acute hospital services by adults with a learning disability and adults with autism in the east of England has limited the evidence that could be used to quantify possible savings. The activity and savings information provided are indicative and conservatively reported. They are also likely to reflect an under reporting of activity and therefore savings. The indicative savings which it has been possible to identify are £196,500 per year for an acute hospital serving a 350,000 population. This level of savings across the 17 acute hospitals in the east of England equates to £3,340,000 each year, It is essential that good flagging and information systems are developed and refined so that potential areas and levels of savings can be identified, monitored and reported on. The savings achieved will accrue across the health economy and so requires joint work by acute hospitals and commissioners.

3. **Guidance for effective alert and information systems to deliver and monitor improved quality and cost savings** (Chapter 6).

   Out of 17 acute hospitals in the east of England, four currently have an electronic alert system for adults with a learning disability, and none for adults with autism. Very few have agreed systems with GPs to indicate that someone has a learning disability or autism at the point of referral or discharge. The guidance outlines why these are key areas for improvement and provides guidance to Trusts, commissioners and GP's on how effective systems can be achieved. The key information on demand, quality of care, costs, savings and meeting CQC and legal requirements which an electronic hospital alert system can potentially provide is also outlined.

4. **A Quality Assurance Framework with a model for self assessment and an agreed improvement plan** (Chapter 7).

   This Framework, focussed specifically on acute hospitals, builds on work in South West England and on the national Learning Disability Self Assessment for local health systems. It sets out five Top Targets, each with a number of objectives and standards. Acute hospitals should complete their self assessment with the involvement of people who have used its services and family carers, with the proposed RAG levels validated by commissioners and the learning Disability Partnership Board. The agreed RAG levels will then inform an agreed and prioritised improvement plan. This Framework is not intended to be an exercise in self assessment alone. It should be used to support and drive action for improvement in agreed areas. It is likely to be best undertaken every two years and should be coordinated with local self assessments of how well the whole heath system is meeting the needs of adults with a learning disability and/or autism.

5. **A Staff Development Framework** (Chapter 8).

   The Staff Development Framework looks to improve skills, knowledge and awareness of all staff who are involved in or who contribute to the patient pathway for adults with a learning disability or adults with autism. It is, therefore, relevant to a wide range of staff e.g. clinicians, receptionists, bed managers, porters, ambulance staff. The framework offers four levels of training starting from awareness raising at induction through to specific skills and knowledge training for ward based learning disability 'champions'. Ensuring that all staff have appropriate skills, knowledge and attitudes is key to ensuring that the agreed pathways deliver high quality care for each individual.

6. **Effective role and organisational reporting structure for Acute Hospital Learning Disability Liaison Nurses** (Chapter 9).

   It is clear from national and local evidence that having a liaison nurse in place to work with and address issues in relation to adults with a learning disability or autism substantially improves the quality of care provided. This has an impact in terms of the work undertaken with individuals and in terms of systemic improvements to patient pathways and services. Four recommendations are made to achieve an effective role and reporting structure for learning disability liaison nurses. These include ensuring that: there is a Trust wide improvement plan, not one solely for the learning disability liaison nurse; the liaison nurse reports directly to a senior manager with direct access to the Trust Board; the post is substantive, clinically qualified and has sufficient capacity for the workload; and the post is employed by the acute hospital trust.

7. **Recommended protocols and joint agreements** (Chapter 10).

   Delivery of an effective patient pathway will be greatly strengthened through a number of protocols, agreements and guidance notes. Some of these will be internal to the acute Trust e.g. reasonable adjustments to Bed Management Protocols. A number of protocols and agreements will need to be jointly developed and agreed with a range of partners e.g. commissioners, local authorities, specialist learning disability services. Guidance on the role of family carers whilst someone is in hospital should be developed with family carers, adults with a learning disability or autism and commissioners. As well as improving the quality of care and effectiveness of pathways, some protocols will also improve efficiency e.g. a Protocol for Additional Funding and External Staffing will reduce the significant time and effort spent by Trust staff, commissioners and local authorities on these often frustrating and repetitive negotiations.

8. **An index of good practice in the east of England** (Chapter 11).

   This work has shown there to be a significant amount of good practice in the east of England. The index summarises that which has been identified in the same order as the chapters on this report, and provides contact details for further information.

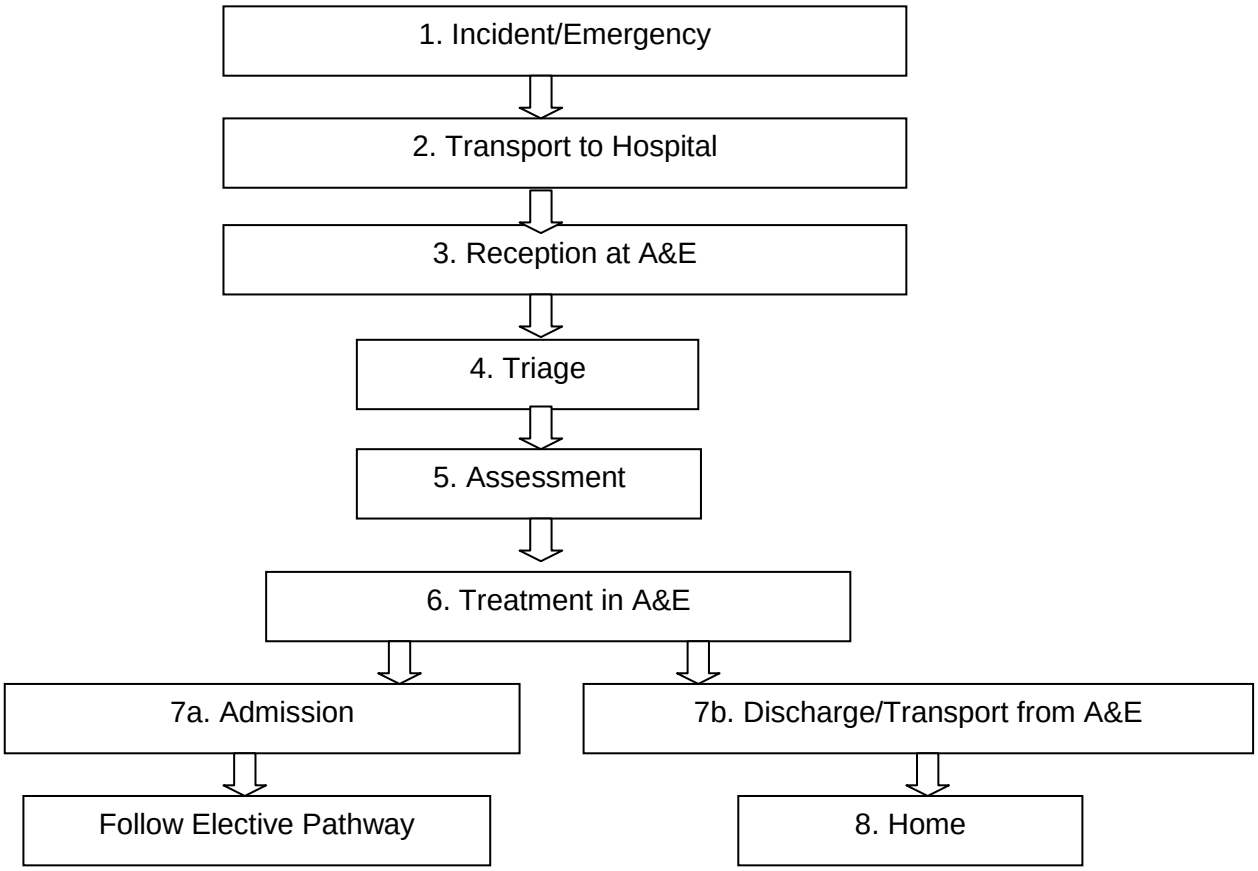
Ten Top Tips from the Project

1. Embed adults with a learning disability, adults with autism and family carers in the planning and evaluation of services
2. Provide corporate leadership and take a strategic approach to improving services for adults with a learning disability and adults with autism.
3. Use the Quality Assurance Framework to assess the current position with commissioners and your Learning Disability Partnership Board, and jointly agree an Improvement Plan.
4. Have an electronic flagging system on the patient information system to ensure that patients' progress through the pathway can be followed and so that you know how many adults with a learning disability and adults with autism use the acute hospital's services
5. Monitor and act on extended lengths of stay; readmissions (within and after 30 days); people who did not arrive; and use of A&E services to improve quality and deliver savings and efficiencies.
6. Agree the pathways for your hospital services and ensure they are known to all staff and embedded in policy and guidance.
7. Ensure that hospital systems and staff can make reasonable adjustments for people, particularly around communication; easy read information; preparation for admission; appointment systems.
8. Deliver the appropriate level of training to all staff.
9. Monitor health outcomes for equality with other comparable groups of patients.
10. 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, and report them to the Trust Board.

3. ACCIDENT AND EMERGENCY PATIENT PATHWAY

This Pathway is for local development to meet the specific characteristics of each health system. It is key that these pathways are agreed as part of clinical governance and known to all acute hospital staff, GP's, ambulance staff and specialist learning disability services.

Guidance on reasonable adjustments is given in Appendix 2



1: An urgent incident / emergency occurs

	Gold Standard
Who	The person, a family carer, a paid supporter, the GP
What	Contacts NHS Direct, emergency services or takes the person to hospital.
When	Immediately
How and Reasonable Adjustments	Each adult with a learning disability or autism has a card giving key information and contact details.

2: Transport to Hospital

	Gold Standard
Who	A family carer, paid supporter or ambulance
What	Transport the person to hospital A&E Dept.
When	Immediately
How and Reasonable Adjustments	For an Emergency the person should bring: • A card with emergency information. Where a condition has become acute (in some hospitals, the majority of incidents) the person should bring as circumstances allow: • A card with emergency information. • Patient /Hospital Passport • Health Action Plan • Medication or prescription

3: Reception at Accident and Emergency Department

	Gold Standard
Who	Reception staff Security staff Family carers / support staff to stay with the patient
What	Person is 'checked in' to the A&E service Reception staff to identify if the person is or may be someone with a learning disability or autism. Reception staff to enter the agreed learning disability / autism alert on the hospital PAS system.
When	When the person comes to reception.
How and	Reception staff to:

Reasonable Adjustments	• Identify if someone is or may be someone with a learning disability or autism (Refer to the agreed Protocol for Reception Staff and Security Staff). • Ask for and use any information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan • Contact made with a named primary contact if this individual is not already present. • Input the alert which signifies someone has a learning disability or autism. Waiting time in A&E: • Provide an easy read information sheet for everyone indicating the likely waiting time and when the time starts. • Consider use of other supports e.g. a fast track process; a quiet room; a 'buzzer' system which tells people when their turn to be seen has arrived (allows people to have some freedom to walk around).

4: Triage

	Gold Standard
Who	Triage nurse Family carers / support staff staying with the patient
What	Complete the triage process
When	When the person arrives at Triage: note the possible need to fast track to and through Triage
How and Reasonable Adjustments	Triage staff to: • Identify if someone has or may have a learning disability or autism where this becomes newly apparent. • Input the alert which signifies someone has a learning disability or autism. • Ensure the person gives consent (if able) to the family carer or paid supporter participating in the triage process. • Contact other services if more information is required e.g. CLDT (within Caldicott requirements) • Contact the Acute Hospital Learning Disability Liaison Nurse (AHLN)? • If AHLN not available, who is the best contact? • Consider the person's mental capacity, consent and best interests • Provide / use easy read materials for information about procedures • Use an agreed option if the person becomes distressed e.g. a fast track process; a quiet room; a 'buzzer' system which tells people when their turn to be seen has arrived (allows people to have some freedom to walk around). • Use of information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan • Transfer the alert which signifies someone has a learning disability or autism for next stage of pathway.

5: Assessment

	Gold Standard
Who	Assessment staff Family carers / support staff staying with the patient
What	Assessment of medical conditions with increased interventions, some of which are likely to be invasive.
When	Standard to be agreed for period of assessment
How and Reasonable Adjustments	Assessment staff to: • Note and respond to the learning disability / autism alert • Identify if someone has or may have a learning disability or autism where this becomes newly apparent. Input the appropriate alert. • Contact the AHLN? • Continuously consider Mental Capacity, consent and best interests • Ask about any advanced directives. • Ensure the person gives consent (if able) to the family carer or paid supporter participating in the triage process. • Provide / use easy read materials for information about procedures • Use options if the person becomes distressed e.g. a fast track process; a quiet room; a 'buzzer' system which tells people when their turn to be seen has arrived (allows people to have some freedom to walk around). • Use of information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan • Begin to consider what the likely outcome will be when assessing the clinical situation and begin to plan discharge requirements. • If the person self discharges, refer to Vulnerable Adults policy, Consider: making an alert; contacting known professionals • Be aware of any follow up that is required if the person leaves prior to treatment, but does not alert or discuss with staff (informal discharge). • Transfer the learning disability / autism alert • Transfer information to avoid the need for repeated questions (includes communication and personal care)

6: Treatment in A&E

	Gold Standard
Who	Appropriate clinical staff
What	Treatment of medical conditions with increased interventions, some of which are likely to be invasive.
When	Standard to be agreed for period of assessment
How and Reasonable Adjustments	Staff delivering treatment in A&E to: • Note and respond to the learning disability / autism alert • Identify if someone has or may have a learning disability or autism where this becomes newly apparent. Input the appropriate alert.

	• Contact the AHLN? • Transfer all information at any handovers (represent high risk); including the flag which signifies someone has a learning disability or autism. • Use any information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan • Consider continuity of staff from assessment to treatment to discharge or admission, or the introduction of new staff during this process (refer to the agreed Bed Management Protocol for people with a learning disability or autism.) • Continuously consider Mental Capacity, consent and best interests • Ask about any advanced directives • Provide / use easy read materials for information about procedures • Use options if the person becomes distressed e.g. a fast track process; a quiet room; a 'buzzer' system which tells people when their turn to be seen has arrived (allows people to have some freedom to walk around). • Ensure early allocation to medical / surgical team and to be seen by a senior doctor. • If the person self discharges, refer to Vulnerable Adults policy. Consider: making an alert; contacting known professionals • Be aware of any follow up that is required if the person leaves prior to treatment, but does not alert or discuss with staff (informal discharge).

The Pathway then follows either:

7a: Admission

	Gold Standard
Who	To be completed locally
What	Admission to a ward for treatment
When	Decision has been made that admission is required
How and Reasonable Adjustments	Staff arranging admission to: • Note and respond to the learning disability / autism alert • Identify if someone has or may have a learning disability or autism where this becomes newly apparent. Input the appropriate alert. • Contact the AHLN? • Transfer all information at handover including the flag which signifies someone has a learning disability or autism. • Use any information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan • Continuously consider Mental Capacity, consent and best interests • Consider continuity of staff from A&E to ward, or the introduction of new staff during this process (refer to the agreed Bed Management Protocol for people with a learning disability or autism.) • Provide / use easy read materials for information about procedures • Use options if the person becomes distressed e.g. a fast track process; a quiet room; a 'buzzer' system which tells people when their turn to be seen has arrived (allows people to have some freedom to walk around). **Link into the Elective Pathway at Stage 7: Care Delivery**

7b: Discharge and Transport from A&E

	Gold Standard
Who	Discharge: Nurse, Doctor, AHLN (where available). Transport: A family carer, paid supporter, ambulance or ambulance transport service
What	Discharge from A&E and transport to home
When	Following treatment or the decision that no further action is required.
How and Reasonable Adjustments	If referred for an Outpatient Appointment, refer to the Elective Care Pathway. Staff arranging discharge and transport home to: • Note and respond to the learning disability / autism alert • Involve the AHLN where possible. This can be dependent upon initial arrival at A&E • Consider any reasonable adjustments needed for the transport to take the patient home • Use any information the person has brought with them e.g. Emergency Card; Patient /Hospital Passport; Health Action Plan. • Continuously consider Mental Capacity, consent and best interests. • Provide / use easy read materials for information about the Discharge Plan, medication and any follow up appointments to take home. • Update the person's Hospital Passport if available • Be aware of deprivation of liberty issues, ensuring there is consideration as to whether it is suitable for the patient to return home, not just whether they want to. • If the individual is living on their own or in supported living, be aware of options available when bridging the gap between treatment and discharge. If it is not appropriate for them to return to their living environment or there is uncertainty surrounding discharge, consider Medical Assessment Unit. A discharge summary is sent to the GP by letter and / or e-mail, including: • An agreed learning disability or autism alert • Diagnosis • Treatment • Medication on admission • Medication on discharge • Discharge plan summary Information about the admission and discharge sent immediately to any key involved people e.g. a family carer, community learning disability team, support service as agreed with the patient. To include the presenting problem; diagnosis; action taken; discharge arrangements. Any arranged transport to be appropriate to the person's needs

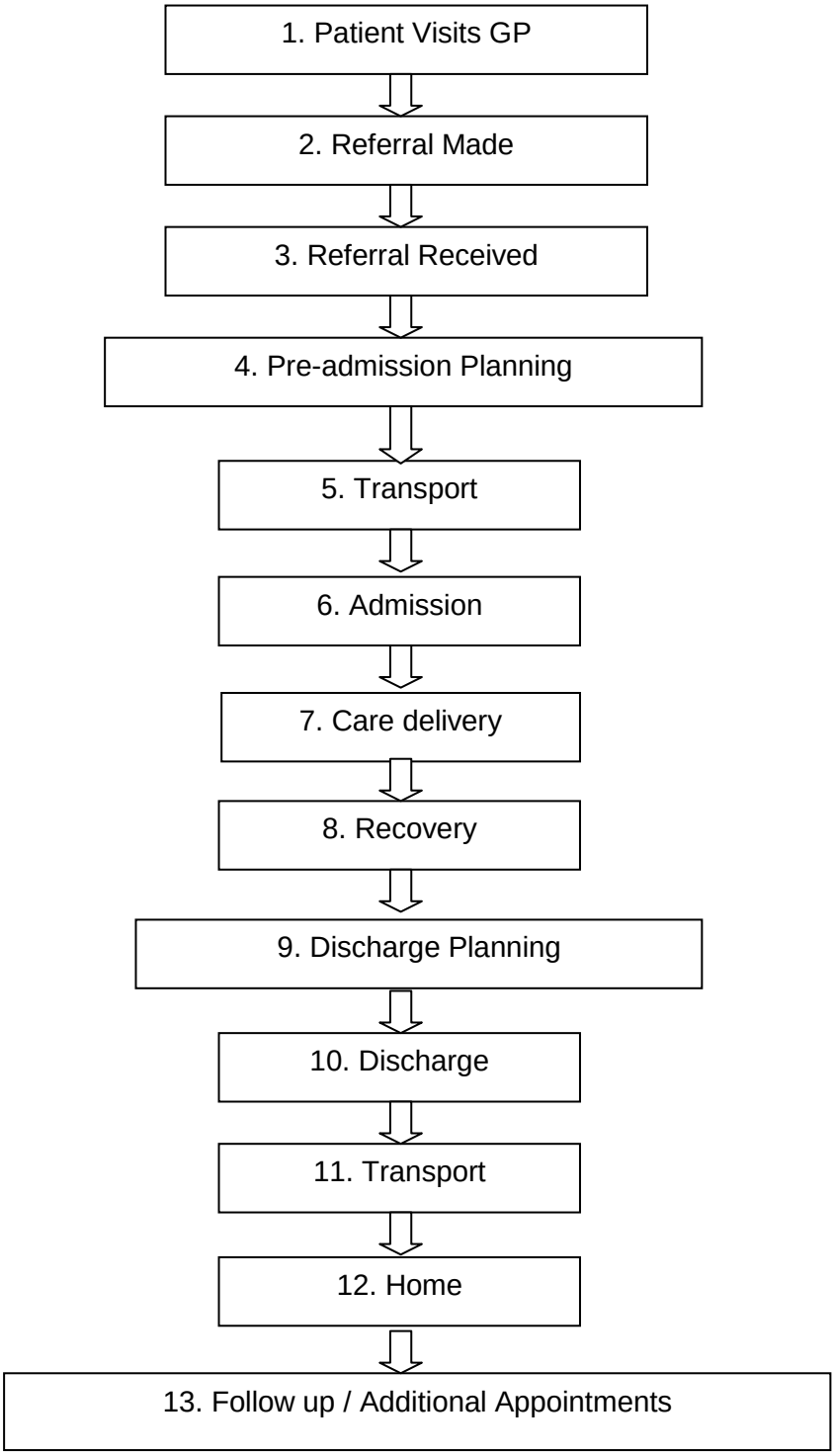
8: Home

	Gold Standard
Who	Patient Family carers/parents/friends Community Learning Disability Team if appropriate (social worker, community nurse and others) Any care provider to be involved post discharge. GP
What	Arrival home and the need to ensure appropriate follow up once discharged
When	Upon arrival home
How and Reasonable Adjustments	Easy read Discharge Plan and (where updated) Patient / Hospital Passport available for family carers and / or involved paid staff as appropriate Review undertaken by community services if appropriate. Any unexpected changes to the person's condition are notified to the GP or, if necessary, the emergency services.

4. ELECTIVE IN-PATIENT AND DAY HOSPITAL PATIENT PATHWAY

This Pathway is for local development to meet the specific characteristics of each health system. It is key that these pathways are agreed as part of clinical governance and known to all acute hospital staff, GP's, ambulance staff and specialist learning disability services.

Guidance on reasonable adjustments is given in Appendix 2



1. Patient Visits GP

	Gold Standard
Who	The person, a family carer, a paid supporter, the GP
What	Contacts GP, appointment arranged and takes place.
When	Earliest opportunity
How and Reasonable Adjustments	The GP Register includes an alert that the adult (aged 18+) has a learning disability or autism (through the Learning Disability DES for the former). The Learning Disability / autism alert indicates the need for reasonable adjustments to be made for the individual e.g. an appointment at beginning or end of surgery; an extended appointment time; personally telling the person it is their turn. Each adult with a learning disability has: • an annual health check, • their Patient /Hospital passport • their Health Action Plan GP has access to the person's: • annual health check • Patient / Hospital passport • Health Action Plan This does not currently apply to adults with autism.

2. Referral Made

	Gold Standard
Who	GP
What	Referral sent to hospital with the agreed learning disability or autism alert used.
When	Earliest opportunity/When appropriate
How and Reasonable Adjustments	Referral letter to include: • An agreed learning disability or autism alert • Any known reasonable adjustments required • Any mental capacity needs including the role of a family carer or IMCA, with the person's permission. • Any additional/important information including additional support/care that would be needed to facilitate admission. • Medication or prescriptions currently in place. Links to POD's Scheme? • Anyone else to whom information about appointments should be sent e.g. family carer, community learning disability team?

	If an electronic referral system is available, referral to include as much of the above information as possible, supported by a referral letter if necessary.

3: Referral Received

	Gold Standard
Who	Hospital admin staff
What	Letter of referral received and signposted to appropriate service / individual for action.
When	When the referral arrives.
How and Reasonable Adjustments	Checks made if the person is previously known to the hospital. Learning disability or autism alert entered on patient record, either hard copy or electronic (Patient Administrative System (PAS)). Acute Hospital Learning Disability Liaison Nurse (AHLN) informed?

4: Pre-admission Planning

	Gold Standard
Who	Clinical staff to be identified Acute Hospital Learning Disability Liaison Nurse Bed Managers Family carers Community Learning Disability Team Support staff
What	Plan the outpatient appointment or admission to ensure best possible experience
When	On receipt of the referral by the appropriate hospital department.
How and Reasonable Adjustments	Offer a pre-admission planning meeting with the person and other people they want to attend e.g. family, Community Learning Disability Team, support staff: • Letter to go to the person and any other key person identified e.g. family carer, community learning disability team. • Any letters to be in easy read format and individualised • Any accompanying education / information materials to be in easy read or DVD formats e.g. about in-patient or out-patient services • Venue of the person's choosing. • Ask for the person to bring their Patient / Hospital passport and Health Action Plan to the meeting (if these have been completed). • AHLN to be involved? e.g. if no family carer or community services involved, or there are complex needs.

	Pre-admission planning meeting to agree plans and responsibilities for admission and outline plans for discharge: see suggested agenda at the end of this Pathway. If pre-admission meeting is declined, ask the person with support e.g. family carer, support worker, to complete the pre-admission document and return in good time for admission. A named nurse on the ward or outpatient service to be used is allocated the responsibility for implementing pre-admission plans. Information from the pre-admission meeting or document is put in the information system of the relevant hospital department(s) Outpatient appointment or admission date is confirmed with the person and other key people identified during pre-admission meeting. All hospital departments involved in the person's treatment place a learning disability or autism alert on their information systems (electronically or hard copy). Any additional supports and funding (staff or equipment) are identified and in place before admission as per the agreed Protocol for Additional Funding and Supports.

5: Transport

	Gold Standard
Who	Family carers/parents/friends Ambulance
What	Transport to the hospital for outpatient appointment or admission as agreed at the pre-admission meeting. If Ambulance required, GP to order.
When	On an agreed date and time
How and Reasonable Adjustments	Any reasonable adjustments for transport identified at the pre-admission meeting should be in place. An easy read introduction to travelling by ambulance to be provided beforehand.

6: Admission

	Gold Standard
Who	Medical Receptionists Other hospital staff AHLN if agreed pre-admission Patient Family carer Support worker (if agreed)
What	Admission to outpatients or hospital ward
When	Upon arrival at the hospital
How and Reasonable Adjustments	Reception and admitting staff to: • Note and respond to the alert which signifies someone has a learning disability or autism. • Access and use the full information provided and agreed pre-admission • Confirm any role or inputs of family carers or support staff agreed pre-admission, and facilities they require. • Use any information the person has brought with them e.g. Patient / Hospital passport; Health Action Plan • Provide / use easy read materials for information about procedures • Transfer all information at any handover • Involve the AHLN if part of the admission plan

7: Care Delivery

	Gold Standard
Who	Relevant hospital staff (will be determined by reason for admission) Family carer if agreed Support worker if agreed
What	Delivery of relevant investigations and care in out-patient or in-patient settings. Movement through necessary departments, e.g. surgery prep, surgery etc.
When	Through the period of being in the hospital
How and Reasonable Adjustments	All staff in out-patient or in-patient settings to: • Note and respond to the alert which signifies someone has a learning disability or autism. • Access the full information provided and agreed pre-admission • Confirm any role or inputs of family carers or support staff agreed pre-admission, and facilities they require. • Use any information the person has brought with them e.g. Patient / Hospital passport; Health Action Plan • Transfer all information at any handover • Plan for continuity of staff where possible, or appropriate introductions to new staff during the process.

	• Continuously consider Mental Capacity, consent and best interests • Consider involvement of the AHLN • Provide / use easy read materials for information about procedures, pain management, ++++++ • If attending Theatre, refer to Protocol for Theatre and Recovery • If any bed moves are suggested, refer to the agreed Protocol for Bed Management for People with a Learning Disability or Autism.

8: Recovery

	Gold Standard
Who	Patient Hospital staff Family carer if agreed Support worker if agreed
What	Any care delivery and support needed in order to support the patient in their recovery whilst using out-patient or in-patient services.
When	Following treatment/surgery/procedure. Recovery may be ongoing with additional treatment in some circumstances
How and Reasonable Adjustments	All staff in out-patient, in-patient ward and recovery room settings: • Note and respond to the alert which signifies someone has a learning disability or autism. • Access the full information provided and agreed pre-admission • Decide where recovery will best take place. Acute setting is not always the best or right place. • If the person has been in Theatre, refer to Protocol for Theatre and Recovery • Confirm any role or inputs of family carers or support staff agreed pre-admission, and facilities they require. • Use any information the person has brought with them e.g. Patient / Hospital passport; Health Action Plan • Transfer all information at any handover • Plan for continuity of staff where possible, or appropriate introductions to new staff during the process. • Consider involvement of the AHLN • Continuously consider Mental Capacity, consent and best interests • Provide / use easy read materials for information about procedures, pain management, the recovery process, length of time, what to expect; ++++++ ++++++ • If any bed moves are suggested, refer to the agreed Protocol for Bed Management for People with a Learning Disability or Autism.

9: Discharge Planning

	Gold Standard
Who	Patient Hospital staff Family carers/parents/friends Community Learning Disability Team if appropriate (social worker, community nurse and others) Any care provider to be involved post discharge.
What	To plan and facilitate the discharge of the patient, whether this is back to their own home, care home, or a step down service.
When	When patient and staff feel that it is appropriate to be discharged from the acute setting
How and Reasonable Adjustments	Identify a named nurse responsible for the individual's discharge planning Discharge planning should address the key areas listed at the end of this Pathway. Good communication and coordination is essential; specific meetings may be required. Consult the patient and get their views on what is happening and any support they may need Involve, as appropriate, family carers; CLDT staff (health and social care); support staff; hospital social work team; AHLN; transport if required; +++ Pharmacist to review medicines and their administration before discharge Provide the discharge plan in an easy read format. Update the person's Patient / Hospital Passport, Health Action Plan to include the discharge plan and, if necessary, Emergency Card Ensure community services are agreed and in place before discharge Clearly communicate the discharge plan with everyone involved and with all services before discharge.

10: Discharge

	Gold Standard
Who	Patient Hospital staff, (Doctor, Ward Nurses, AHLN) Family carers/parents/friends Community Learning Disability Team if appropriate (social worker, community nurse and others) Any care provider to be involved post discharge.
What	Discharge from hospital

When	Day of Discharge
How and Reasonable Adjustments	Easy read documentation is provided to explain how the discharge process works Periods of uncertainty and any unnecessary moves around the hospital are avoided e.g. going to the discharge lounge if staying by the bed is preferable If agreed at discharge planning meeting, a named individual stays with the person and provide real time updates as to what is happening. The discharge summary is signed off to meet any preferred time of discharge The Discharge Pack is given to the person agreed at the Discharge Planning Meeting: • Updated Patient /Hospital Passport • Updated Health Action Plan • Emergency card • Easy read Discharge Plan • Medication and prescriptions • Key contacts Copy of the easy read discharge plan to be given specifically to the patient A discharge summary is sent to the GP by letter and / or e-mail, including: • An agreed learning disability or autism alert • Diagnosis • Treatment • Medication on admission • Medication on discharge • Discharge plan summary

11: Transport

	Gold Standard
Who	A family carer, paid supporter, ambulance or ambulance transport service
What	Transport to home as agree at the Discharge Planning meeting
When	Following discharge planning and sign off of discharge summary
How and Reasonable Adjustments	Any reasonable adjustments for transport identified at the Discharge Planning meeting should be in place. An easy read introduction to travelling by ambulance to be provided beforehand.

12: Home

	Gold Standard
Who	Patient Family carers/parents/friends Community Learning Disability Team if appropriate (social worker, community nurse and others) Any care provider to be involved post discharge. GP
What	Initial support when arriving home
When	Arrival home and initial period of support
How and Reasonable Adjustments	The Discharge pack is left at the accommodation. The pack is handed to an identified person if agreed in the discharge plan. The support agreed at the discharge meeting and set out in the Discharge Plan is in place at the agreed time at the agreed level of support Support is available to the person's family carer if identified and agreed in the Discharge Plan

Step 13: Follow up/Additional appointments

	Gold Standard
Who	Patient Family carers/parents/friends Community Learning Disability Team if appropriate (social worker, community nurse and others) Any care provider to be involved post discharge. GP
What	Follow up to ensure safety and well being of the person on discharge and return home
When	In the days / weeks following discharge
How and Reasonable Adjustments	Health and social care supports as identified in the Discharge Plan are in place Any unexpected changes to the person's condition are notified to the GP or, if necessary, the emergency services. Any changes in support needs are identified or referred to the Community Learning Disability Team for assessment or review. Any follow up appointments in the discharge plan are kept.

Planning information

1. Pre-admission planning: key areas to be considered:

- transport to hospital
- any introductory visits required
- any needs during admission
- medical and medication needs
- mental capacity, consent and best interests
- risks and how they should be managed
- how the person best communicates and received communications
- physical and sensory needs
- additional nursing support needs
- any specific equipment required and how this will be sourced
- support needs in hospital from family carers or support staff
- any facilities family carers or support staff might need to access
- responsibility for funding any additional supports
- information (Patient /Hospital Passport / Health Action Plan)and medication the person should bring
- who will be involved in discharge planning
- any needs around bed moves and continuity of staff

2. Discharge planning: key areas to be considered:

- The plans for discharge agreed at the pre-admission meeting.
- Mental capacity, consent, best interests, risks and how they should be managed.
- If challenging behaviour exists, how this could impact on discharge and further recovery.
- Medical and medication needs, including pharmacology and the administration of any medicines. Use of PODs scheme?
- Risks and how they should be managed
- Additional support needs to be met on going home
- Appropriate use of any intermediate care, step down and rehabilitation services
- Any specific equipment required, how this will be sourced and taken to the person's home
- Any need for the discharge to be at a particular time of day e.g. early / mid day / late afternoon.
- Transport from hospital
- Any re-introductory visits required
- Any health needs of family carers
- Responsibilities of hospital staff, community learning disability team, AHLN, hospital social work team, any community based services involved and family carers for implementing the discharge plan.
- Who needs to have a copy of the discharge plan
- Who will take the Discharge Pack when the person leaves hospital? This includes: Emergency Card; updated Patient /Hospital Passport; Updated Health Action Plan; accessible Discharge Plan; medication and prescriptions; key contacts
- Should the Discharge Pack be handed over to anyone when the person arrives home, or be left with the person
- Identify who may be the named person to stay with the person to keep them informed and avoid unnecessary anxiety and distress

5. INDICATIVE USE OF ACUTE HOSPITAL SERVICES BY ADULTS WITH A LEARNING DISABILITY AND POSSIBLE COST SAVINGS

1. Introduction

This section of the QIPP provides guidance on the indicative use of acute hospital services by adults with a learning disability, expected areas of cost savings and some possible levels of savings.

Indicative activity and cost savings are given as it has proved very difficult (as at March 2011) to gain consistent or comprehensive data from acute hospitals in the east of England in relation to the use people with a learning disability make of their services. Currently, 4 out of 17 hospitals have achieved electronic flagging systems, with these at varying stages of development in terms of using the data available to provide reliable information. The information available also applies only to people with a learning disability, as data collection has not included people with autism.

Consequently, it is not currently possible to achieve comprehensive information through which to fully understand activity levels, costs and possible savings in the following areas:

People with a learning disability	
Accident and Emergency	Attendances
In-patients following emergency admission	Admissions
	Readmission within 30 days
	Readmission after 30 days
	Additional bed days
Elective in-patients	Admissions
	Did not arrive
	Arrived, unable to go ahead
	Readmission within 30 days
	Readmission after 30 days
	Additional bed days
Elective out-patients	Attendances
	Did not arrive
	Arrived, unable to go ahead

The Guidance on Effective Flagging and Information Systems (Chapter 6) addresses how these systems can be developed to provide this information.

The information and estimates provided below form a basis for each local health system to undertake their own investigations into activity, costs and savings. Some savings will accrue to acute Trusts whilst others will accrue to commissioning budgets. Work will, therefore, be best taken forward jointly by acute Trusts and commissioners. Savings figures have been developed for an acute hospital serving a population of 350,000 – approximately the average for hospitals in the east of England.

2. Indicative Use of Acute Hospital Services by People with a Learning Disability

The indicative activity information has been developed using data from three hospitals in the east of England:

	Hospital 1	Hospital 2	Hospital 3
Population of main catchment area	350,000	334,000	600,000
Number of acute hospital beds	970	677	1100
Number of people with a learning disability in the population (2%)	7,000	6,680	12,000

These hospitals have been able to provide information of some reliability through having either (or both):

- An electronic flag for learning disability on their central patient information system, albeit that there are difficulties with some inconsistency in the flags used to indicate different degrees of learning disability, and information still being refined through audit. This has demonstrated the need for acute hospitals to use a single administrative flag on their electronic patient information system rather than rely on clinical codes (see Chapter 6).
- A long standing, well established Learning Disability Liaison Nurse in post who has been able to provide partial but reliable information from their own records. However, this will be an under reporting of activity as there are people who use hospital services of whom the liaison nurse will not be notified.

Liaison Nurses report that a large number of people with a learning disability use hospital services who are not known to specialist learning disability services. This correlates with national research which reports that 2% of the population has a learning disability whilst an average of 0.47% are known to specialist learning disability services (Learning Disability Public Health Observatory: http://www.improvinghealthandlives.org.uk/numbers/)

3. Summary of key indicative activity, costs and potential savings

3.1 **Accident and Emergency:** there are high levels of activity by people with a learning disability using A&E services, with a range of 199 – 284 annual attendances for a general population of approximately 350000 people:

- Feedback from Liaison Nurses indicates the need to investigate and reduce repeat attendees particularly where this occurs through:
  - people having acute episodes of chronic conditions e.g. epilepsy
  - people from specific services in the local area repeatedly attending.
  - Agreeing a *Protocol for flagging and reviewing repeat attendances at A&E and appropriate actions* will increase efficiency and reduce costs in this area (see Chapter 10: Protocols and Agreements to Support the Acute Hospital Pathway for People with a Learning Disability)

- Further savings are available through improved pathways which deliver more efficient clinical processes for people e.g. effective triage which identifies if someone has a learning disability; paying attention to mental capacity; providing accessible information.

3.2 Emergency admissions: 253 people per year are expected to be admitted as an emergency to Hospital 3 at a cost of £1,924,000. For a catchment area of 350,000 population, this indicates 148 emergency admissions at a cost of £1,122,000.

- Readmissions within 30 days of discharge:
  for Hospital 3, 64 people (25% of admissions) are projected as being readmitted within 30 days of discharge at a cost of £348,000. An indicative reduction of 25% through better discharge and care planning = £87,000. For a hospital serving a catchment area of 350,000 this indicates 37 readmissions within 30 days and indicative savings at a 25% reduction of £51,000.
- Readmissions over 30 days after discharge:
  for Hospital 3, 104 people (41%) are projected as being readmitted over 30 days after discharge at a cost of £565,000. An indicative reduction of 25% through better discharge and care planning = £141,000. For a hospital serving a catchment area of 350,000 this indicates 61 readmissions over 30 days and indicative savings at a 25% reduction of £82,000
- Additional bed days:
  Improved pathways which pay attention to efficient, timely use of resources e.g. attention to mental capacity, good discharge planning, will contribute to a reduction in additional bed days.

3.3 Elective care: Figures suggest between 84 and 136 people with a learning disability are admitted for elective surgery each year per catchment area of 350,000 people:

- Readmissions over 30 days after discharge:
  for Hospital 3, 52 people (22% of elective admissions) are projected as being readmitted over 30 days after discharge at a cost of £364,000. An indicative reduction of 25% through better discharge and care planning = £91,000. For a hospital serving a catchment area of 350,000 this indicates 30 readmissions over 30 days and indicative savings at a 25% reduction of £53,000
- Readmissions within 30 days of discharge:
  Information from all three hospitals indicate that for a hospital serving a population of 350,000, there will be 6 readmissions following elective care within 30 days of discharge at a cost of £42,000. An indicative reduction of 25% in readmissions through better discharge and care planning = £10,500
- Procedures not going ahead:
  4% of known elective admissions to hospital did not go ahead through people not arriving or procedures not being able to go ahead. It has been difficult to quantify the cost of this, but improved preparation before the day of admission eg a DVD giving information about admission; pre-admission meeting for people with complex needs.
- Additional bed days:

Improved pathways which pay attention to efficient, timely use of resources e.g. attention to mental capacity, good preadmission and discharge planning, use of accessible information will contribute to a reduction in additional bed days.

- A jointly agreed *Protocol for Additional Funding and External Staffing*: Having this jointly agreed Protocol in place will increase efficiencies in staff time across all agencies (see Chapter 10: Protocols and Agreements to Support the Acute Hospital Pathway for People with a Learning Disability).

3.4 Elective out-patients: A wide disparity in numbers are reported as attending out-patient services (from 113 to 230 people per 350,000 of general population annually) indicating that recording is a significant issue and activity is likely to be underestimated.

- There is significant variation in the reported levels of people not arriving or procedures not being able to go ahead (from 10 to 51 per 350,000 of general population). Levels of non-attendance and the causes will require investigation by each hospital. Significant savings are potentially available through improved pathways e.g. accessible letters and information; pre-admission planning and visits.

3.5 Acute Hospital Liaison Nurses: Evidence at Norfolk and Norwich University Hospital indicates that 39% of people with learning disabilities had extended lengths of stay (across emergency and elective admissions) before a Liaison Nurse was appointed. Potential savings will be greatest in hospitals where there is no Liaison Nurse (3 acute hospitals in the east of England) or not long established (5 hospitals where Liaison Nurses have been in post for between 2 and 7 months as at March 2011).

3.6 Summary of indicative activity and potential savings where identified

Potential savings for an acute hospital serving 350,000 people, where it has been possible to identify them with current information:

People with a learning disability		Annual indicative activity	Annual Indicative *costs* /savings
Accident and Emergency	Number of people attending	199 - 284	N/K
In-patients following emergency admission	Number of admissions	148	*£1,122,000*
	Readmission within 30 days	37	£51,000
	Readmission after 30 days	61	£82,000
	Additional bed days	N/K	N/K
Elective in-patients	Number of admissions	84 - 136	*£573,000 - £870,000*
	Did not arrive	3	N/K
	Arrived, unable to go ahead		
	Readmission within 30 days	6	£10,500
	Readmission after 30 days	30	£53,000
	Additional bed days	N/K	N/K
Elective out-patients	Number of people	42 - 231	N/K
	Did not arrive	N/K	N/K

	Arrived, unable to go ahead	N/K	N/K
Indicative savings for an acute hospital servicing a population of 350,000			**£196,500**

Achieving this level of savings at each acute hospital in the region (17) = £3,340,000 p/a

4 Detailed information collected.

4.1 Accident and Emergency

People with a learning disability	Hospital 1 (Jan – Dec 2010)	Hospital 2 (Jan – Dec 2010)
Population of main catchment area	350,000	334,000
Number of people with a learning disability in the population (2%)	7,000	6,680
Number of people attending A&E	199	284

4.2 Emergency admissions (through A&E and directly to hospital)

Costs for additional bed days in 4.2 and 4.3 are calculated as an average of all national HRG tariffs: £230 per day

People with a learning disability		Hospital 1 (Jan – Dec 2010)	Hospital 2 (Jan – Dec 2010)	Hospital 3 (12 months pro rata from part year figures)
Population of main catchment area		350,000	334,000	600,000
Number of acute hospital beds		970	677	1100
Number of people with a learning disability in the population (2%)		7,000	6,680	12,000
In-patients following emergency admission	Number of admissions	-	-	253
	Cost of admissions	-	-	£1,924.000
	Readmissions within 30 days	-	-	64
	Cost of readmissions within 30 days (excl 1st admission)	-	-	£348,000
	Readmissions over 30 days	-	-	104
	Cost of readmissions over 30 days (excl 1st admission)	-	-	£565,000
	Additional bed days Cost @ £230 p/day	20 people: 304 days. Cost: £69,920	7 people: 278 days. Cost: £63,940	-

4.3 Admissions for elective care

People with a learning disability		Hospital 1 (Jan – Dec 2010)	Hospital 2 (Jan – Dec 2010)	Hospital 3 (12 months pro rata from part year figures)
Population of main catchment area		350,000	334,000	600,000
Number of acute hospital beds		970	677	1100
Number of people with a learning disability in the population (2%)		7,000	6,680	12,000
Elective in-patients	Number of admissions	91	80	233
	Cost of admissions	£581,000 (estimate)	£510,000 (estimate)	£1,490,000
	DNA	-	2	-
	Arrived but unable to go ahead	-	1	-
	Readmission within 30 days	6	4	8
	Cost of readmissions within 30 days (excl 1st admission)	£42,000 (estimate)	£27,994 (estimate)	£56,000
	Readmissions over 30 days	-	-	52
	Cost of readmissions over 30 days (excl 1st admission)	-	-	£364,000
	Additional bed days Cost @ £230 p/day	3 people: 9 days. Cost: £2,070	1 person: 66 days Cost: £15,180	-

4.4 Elective out-patients

People with a learning disability		Hospital 1 (Jan – Dec 2010)	Hospital 2 (Jan – Dec 2010)	Hospital 3 (12 months pro rata from part year figures)
Population of main catchment area		350,000	334,000	600,000
Number of people with a learning disability in the population (2%)		7,000	6,680	12,000
Elective out-patients	Number of people	113	220	84
	%age of learning disability population	1.6%	3.3%	0.7%
	DNA	49	10	-
	Arrived, unable to go ahead	2	-	-

6. GUIDANCE ON EFFECTIVE ALERT AND INFORMATION SYSTEMS FOR ADULTS WITH A LEARNING DISABILITY AND ADULTS WITH AUTISM

Introduction

Currently, very few acute hospital trusts in the east of England have alert systems (electronic or otherwise) for adults with a learning disability or autism who use their services. Neither are there systems in place which provide reliable, comprehensive information for clinical purposes e.g. identifying people so that reasonable adjustments can be made; or for understanding and managing activity and costs. Putting these systems into place is absolutely fundamental to improving acute hospital pathways for adults with a learning disability or autism. This will require local agreement on the areas described in this guidance, and then action to implement these essential systems.

This guidance outlines:

1. Why this is such an important area for improvement
2. Achieving an alert from the GP to the acute hospital that someone has a learning disability or autism
3. Implementing a learning disability / autism alert system within the acute hospital patient information system.
4. Achieving an alert to the GP when the person is discharged.
5. Information to be provided by a hospital alert system

1. Why have an alert system and good information about adults with a learning disability and adults with autism using an acute hospital?

1. To improve quality of care and safeguarding of individuals by:
   - Highlighting to hospital staff that any potential risks for the person through their learning disability or autism should be identified and assessed proactively and early in the pathway, and then addressed through reasonable adjustments.
   - Sharing information about the adjustments an individual requires as they move through the health system

2. To drive service improvements by:
   - Understanding and responding to the use adults with a learning disability and adults with autism are making of hospital services
   - Monitoring of health outcomes and an effective pathway for each individual, with remedial action taken where identified.
   - Monitoring that comparable health outcomes and length of stay of adults with a learning disability or autism against other groups of patients are being achieved with an improvement plan to address issues identified

3. To achieve savings and efficiencies by:
   - Providing information on extended lengths of stay; readmissions; repeat attendance at A&E; ‘did not arrive for procedure’ (see section 5)

- Timely/early identification and coordination of pre-admission planning by hospital and community staff
- Making efficient use of hospital staff time by having essential information given once and as a single data set
- Providing the ability to monitor and adjust progress through the pathway for an individual.

4. To reduce corporate risk by:
   - Ensuring that systems are in place which enable commissioners and hospital Trusts to have confidence that adults with a learning disability or autism can be identified for appropriate reasonable adjustments and the best quality care to be in place.

5. To meet regulatory and legal requirements by:
   - Supporting Acute Hospital Trusts to meet their single equality duties
   - Meeting CQC standards, particularly for Outcomes 1 and 4, for planned and emergency admissions of adults with a learning disability or autism

2. Achieving an alert from the GP to the acute hospital that someone has a learning disability or autism

Effective flagging of adults with a learning disability or autism through an alert must start as early as possible in the pathway i.e. at the point of referral for elective care or at the point of contact for emergency care.

2.1 **An alert from the GP** requires agreement of:

- The alert to be used to indicate the person is an adult with a learning disability or autism e.g. a simple administrative alert or the READ code used for QOF or Learning Disability DES registers.
- Who this will be used for i.e. is it only for those people on the GP Learning Disability Register (as per the relevant DES); or anyone the GP identifies as having a learning disability or autism (likely to be a larger number of people)
- How the alert will be transmitted i.e. by hard copy, e-mail or electronically
- The basic data set to be included. The minimum will be a single piece of information to indicate the person has a learning disability or autism. A more useful data set will include:
  - Any known reasonable adjustments required
  - Any mental capacity needs including the role of a family carer or IMCA, with the person's permission.
  - Any additional/important information including additional support/care that would be needed to facilitate admission.
  - Medication or prescriptions currently in place.
  - Anyone else to whom information about appointments should be sent e.g. family carer, community learning disability team?

Agreement of how people will be 'flagged' by GPs will require the involvement of Commissioners (acute hospital and primary care), the acute hospital and GPs.

2.2 **A database of adults with a learning disability held by the acute hospital** will be needed as a minimum data set if an agreement for a flagging process by GPs at referral cannot be reached. This will require:

- An agreed data set of information held on GP learning disability DES registers to be exchanged
- A data sharing / exchange agreement which meets Caldicott requirements *(see good practice section)*
- An exercise to exchange the information and provide any future updates as per the agreement.
- An agreed place in the hospital electronic information system to hold this information. At West Herts Hospital Trust this is the Patient Master Index.

3. Implementing a learning disability / autism alert within the acute hospital patient information system.

A learning disability / autism alert is best achieved electronically to enable the full benefits outlined in Section 1 to be achieved. A physical alert system e.g. through coloured dots on files and at the bedside, is possible and has the benefit of ensuring that all staff working with the person face to face are made aware that they should take account of the person's learning disability *(see good practice section)*. However, it does not easily support the collation, monitoring and reporting of information about adults with a learning disability or autism using the hospital. A combination of the two systems (electronic and physical) might be considered.

3.1 Placing an alert in the hospital system at the point of contact requires:

- Elective care: Administrative staff to recognise the learning disability / autism alert when received from the GP and their responsibilities for entering an alert and any other agreed information in the hospital's Patient Administration System (or equivalent).
- Accident and Emergency: A&E Reception and triage staff particularly to be able to identify if someone has a learning disability and to know their responsibilities for entering an alert and any other information in the hospital's Patient Administration System (or equivalent).
- Clear guidelines for staff and inclusion in relevant training are essential

3.2 An **electronic alert in the hospital information system** is usually achieved as part of the Patient Administration System (PAS) or its equivalent. However, some hospital departments have other patient information systems outside the PAS system e.g. in A&E, radiology.

To achieve an effective patient information system, hospital Trusts will need to:

- Agree where and what alert is entered on the central patient information system to ensure that administrative, reception, clinical and bed management staff can see and respond to it. Experience in hospitals which have used clinical codes as an alert has been that this can cause significant difficulties in effectively retrieving comprehensive information from the system. The number of clinical codes available causes a high

risk of multiple codes being used by different clinicians. It is recommended that a single, administrative alert is agreed and used.

- Identify how the alert is transferred or entered onto other key information systems where it will not be migrated electronically.
- Consider whether a further physical alert system will enhance the quality of care in addition to an electronic system.
- Clear guidelines for staff and inclusion in relevant training are essential.
- Audit the information system to ensure it is complete and up-to-date
- Ensure that the Hospital Patient Information Policy addresses any issues raised by this work and consider whether the Policy needs to specifically refer to people with a learning disability.

4. Achieving an alert to the GP when the person is discharged.

Effective discharge is greatly supported by ensuring that the discharge information passed to GPs includes an agreed learning disability / autism alert.

4.1 **An alert to the GP on discharge** requires agreement of:

- The alert to be used to indicate the person has a learning disability or autism.
- how the alert will be transmitted i.e. by hard copy, e-mail or electronically
- The basic data set to be included. The minimum will be a single piece of information to indicate the person has a learning disability or autism. A more useful data set will include:
  - An agreed learning disability or autism alert
  - Reason for admission
  - Treatment
  - Medication on admission
  - Medication on discharge
  - Discharge plan summary

Agreement to this approach will require the involvement of Commissioners (acute hospital and primary care), the acute hospital and GPs.

5. Information to be provided by an alert system

5.1 Key information on demand, quality of care, costs, savings and meeting CQC and legal requirements which, potentially, can be provided by an electronic hospital alert system includes:

- Numbers of adults with a learning disability or autism using:
  - A&E services (demand; costs)
  - In-patient and outpatient elective services (demand; costs)
  - emergency admissions (demand; costs)
- Extended lengths of stay (quality, costs and savings)
- Readmissions including both within and after 30 days (quality, costs and savings)
- Repeat attendance at A&E (quality, costs and savings)

- 'Did not arrive for procedure' (quality, costs and savings)
- 'Arrived but unable to go ahead' (quality, costs and savings)
- Serious Incidents (quality)
- Use of PALS services (quality)
- Referrals to the IMCA service for advocacy (quality)
- Number of complaints (quality)
- Comparable information of the above against more general patient groupings (quality; Single Equality Duty)
- Information about the above in relation to adults with a learning disability and adults with autism from minority ethnic groups (quality; Single Equality Duty)

6. Good Practice:

6.1 Caldicott Agreements to exchange data.

Hertfordshire PCT and West Hertfordshire Hospital Trusts have finalised such an agreement for a one off exchange of data. Given that the GP Learning Disability Registers apply to people with a learning disability aged 18+, a refresh of the data may be required annually.

6.2 Physical flagging system.

Hertfordshire hospitals use a Purple Dot and Folder system. Purple dots are placed on all medical notes of people with a learning disability and also in bedside locations so that everyone working face to face with the person is alerted to the need for appropriate and reasonable adjustments. A purple coloured folder accompanies the person and is used to hold all key documents:

- Emergency 'grab' sheet
- Health Action Plan
- 'About Me' – a health overview
- Discharge summaries
- A checklist of the person's involvement and mental capacity guidance

7. A QUALITY ASSURANCE FRAMEWORK

1. Introduction

This Quality Assurance Framework aims to enable Acute Hospital Trusts, Commissioners and Learning Disability Partnership Boards to effectively assess the quality of acute hospital services in meeting the needs of adults with a learning disability or autism. The Framework sets out a number of top targets, objectives and quality standards; a self assessment format and methodology; and a format and methodology for an improvement plan.

The framework and process for validation is based on the national Learning Disability Health Self Assessment Framework used in the East of England since 2008/9 but with specific reference to the needs of adults with learning disability or autism in acute hospitals.

2. The Quality Assurance Framework

Quality Assurance is the process of verifying or determining whether a product or service meets or exceeds customer expectations. It is a process driven approach with specific steps to help define and attain goals.

The key outcome of this framework is to support Trusts to develop and agree improvement plans for their services with commissioners and LD partnership boards.

The aims of the quality assurance framework are to enable Acute Hospitals Trusts to:

- Collect data on their own performance
- Look at data on local/national and others strong performance
- Have their self assessment validated by Commissioners and their Learning Disability Partnerships Board
- Agree priorities for improvement and change
- Evaluate progress by subsequent self assessments within the same framework.

The following documents for the Quality Assurance Framework are attached:

- Top Targets, Objectives and RAG Standards: proposed levels and record of evidence
- Validated RAG Levels and Agreed Improvement Plan

Please note that the Framework is referenced to the CQC learning disability draft data collection tool which was scheduled for use in early 2011. Although this is now on hold (as of March 2011), the references have been retained to support cross referencing with any future tools.

The ‘Top Targets’ and objectives in the Framework are:

1. Leadership, management and strategy	**CQC indicator**
1.1 There is clearly identifiable Board and senior management engagement in embedding a learning disability strategy	1a,1c,3,5a,5c 30
1.2 The Trust has policies in place that meet the specific needs of patients with learning disabilities	4,10,11
1.3 Partnership Working takes place at all levels within the organisation.	N/A
2. Care standards, reasonable adjustments and service delivery	
2.1 The Trust employs a registered healthcare practitioner for people with	24

learning disabilities (Acute liaison nurse) and identifies practitioners with extra skills and responsibilities for PWLD	
2.2 The Trusts Single Equality Scheme and action plan reflects the reasonable adjustments required for People with learning disabilities.	3,4,16,26,27,33,34
2.3 People with learning disabilities receive high standards of fundamental care	10,11,28,29,
2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.	8,9,
2.5 People with learning disability receive appropriate nutrition and hydration.	8,11
2.6 People with learning disability are identified prior to admission for elective cases or on admission through Emergency departments	1a, 1b,2,5a,5b,6
2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to <u>all</u> hospital staff.	12,13,14,15
3. Pathways	
3.1 People with learning disabilities attend outpatient appointments and investigations appropriately	1a,6,20,21
3.2 People with learning disabilities attend A&E appropriately	5a,5b,5c,6
3.3 People with learning disability are discharged home in a safe and timely way.	31,32
3.4 Women and partners with learning disabilities have a clear pathway for use of maternity services	16,20,21
4. Involvement and representation of people with learning disability and their carers.	
4.1 People with learning disabilities and their carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation	29,30
4.2 People with learning disability and their carers are fully involved in preadmission planning, care planning and care delivery.	10,28,29
4.3 People with learning disabilities are represented in the workforce.	N/A
5. Information for people with learning disability and their carers.	
5.1 People with learning disability and their carers receive appropriate information prior to planned, emergency or outpatient admissions	20,21,22
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 and carers	19,20,21,22,26
5.3 People with learning disabilities and carers have appropriate information to help them complain, discuss concerns and give feedback.	23,24,25
6. Keeping people safe (Organisational learning)	
6.1 Hospital Trusts demonstrate learning from serious incidents, near misses and all deaths of people with learning disability.	N/A

6.2 The Trust demonstrates learning from other incidents involving people with learning disability	N/A
6.3 The organisation has ways of listening to people with learning disabilities and their carers and learns from this.	17,18, 29,30

3. Methodology

1. Self assessment should be undertaken by Trusts with the involvement of family carers and self advocates.

2. Trusts should asses their current level of performance against the standards for RAG levels 1, 2, 3 and provide evidence to justify this score.

   - All indicators in the RAG indicator must be achieved to reach that level
   - Where only some of the required evidence is achieved Trusts and validation teams may agree to score at Red/Amber or Amber/Green.
   - Include electronic data and audit results as well as documentation.
   - There must be some indication of numbers of staff trained and the quality of that training

3. The proposed RAG level and summary of evidence should be entered in the self assessment document: Top Targets, Objectives and RAG Standards: proposed levels and record of evidence (attached)

4. The self assessment must be validated by Commissioners (those for acute hospitals and for specialist learning disability services) and the local Learning Disability Partnership Board. The Health sub-group of the Partnership Board may take the lead in this work. Adults with a learning disability, adults with autism and family carers should be involved in the validation.

   - Where documents for evidence are submitted to Partnership Boards and advocacy groups the relevant section must be produced in an accessible format

5. An Improvement Plan should be drawn up and agreed by the Hospital, Commissioners and Partnership Board.

   - The Improvement Plan should be realistic and achievable with 5-8 priority objectives to be improved and by how much i.e. move up by one level or move to green.

6. Validated RAG levels and Improvement Plan should be recorded in the Validated RAG Levels and Agreed Improvement Plan document (attached)

7. Trusts should review and report on the improvement plan at intervals agreed with Commissioners and the Learning Disability Partnership Board. Many of the indicators can be cross referenced for other standards e.g. CQC, CQINN

8. Full self assessment and validation should take place each two years and should be timed to feed into broader locality Learning Disability Health Self Assessment as well as other assessments e.g. CQC

4 Acute Hospital Learning Disability / Autism Self Assessment Framework

1. Top Targets, Objectives and RAG Standards: proposed levels and record of evidence

Hospital …… …….. Person completing the form:……..... Date ……

- Trusts should asses themselves and decide which level they think that they reach for each indicator
- Then enter their proposed level and the evidence for this below.
- If all the standards in any of the levels are not achieved Trusts may score themselves red/amber or amber/green
- At the end of the self assessment is document where the proposed levels and the levels then agreed with the validators are recorded. The agreed Improvement Plan should also be recorded in this document.

1. Leadership, management and strategy	**LEVEL 1**	**LEVEL 2**	**LEVEL 3**
1.1 There is clearly identifiable Board and senior management engagement in embedding a strategy for adults with a learning disability or autism	A Senior Trust Board executive is identified as being responsible for the strategy for adults with a learning disability or autism Lead champion/s work across the organisation.	The strategy has been ratified by the Board It determines workforce requirements and puts names to specific roles and responsibilities. A liaison nurse works in the hospital but is either not employed by the Trust or does not have substantive contract with them. There is a flagging system for adults with a learning disability or autism that enables one off reports on the implementation of policy and the Single Equality scheme to be provided	An action plan is in place with strategic aims and implementation deadlines clearly defined and being met; Progress on the action plan is monitored by the Trust Board A commissioning plan is in place which follows Department of Health guidance for adults with a learning disability or autism in acute hospitals. The Trust has taken responsibility for recruiting, employing and managing the acute liaison nurse. This is a substantive post. The acute liaison nurse sits on safeguarding vulnerable adults, patient information and equality and diversity committees. The flagging and information system provides regular reports to the Board on the implementation of policy and the Single Equality scheme to be provided.

Proposed level		Evidence provided		
Red				
Red/amber				
Amber				
Amber/green				
Green				
1.2 The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism		General policies are in place. E.g. Carers policy, nutrition policy	General policies make mention of the specific needs of vulnerable groups including adults with learning disabilities or autism	The Trust has a policy in place for the care and management of adults with learning disabilities or autism. All reviews of current policies consider the needs of adults with learning disabilities or autism
Proposed level		**Evidence provided**		
Red				
Red/amber				
Amber				
Amber/green				
Green				
1.3 Partnership Working takes place at all levels within the organisation.		Evidence of partnership working across organisation boundaries.	Representation on relevant Partnership Boards and health subgroups.	Evidence of multiple agency health and social care system wide learning and collaboration.
Proposed level		**Evidence provided**		
Red				
Red/amber				
Amber				
Amber/green				
Green				

2. Care standards, reasonable adjustments and service delivery	LEVEL 1	LEVEL 2	LEVEL 3
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	Pathway established with the local community learning disability service to support adults with learning disabilities or autism who access hospital services.	Liaison healthcare practitioner working within the hospital but employed and funded through other NHS organisation; Liaison healthcare practitioner recruited and employed by the hospital Trust.	The Trust has a clear strategy for the liaison nurse post and measures its outcomes. Systems in place to ensure liaison healthcare practitioner is covered at times of sickness, annual leave and out of hours. Identifiable link nurse/champion system for all clinical areas having responsibility for adults with learning disabilities or autism in their area.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
2.2 The Trusts Single Equality Scheme and action plan reflects the reasonable adjustments required for adults with learning disabilities or autism. *Guidance on reasonable adjustments is given in Appendix 2*	Range of reasonable adjustments recorded in the Single Equality Scheme action plan;	Demonstrates complex reasonable adjustments are being undertaken, e.g. multiple investigations arranged for the same day, first or last appointment etc. There is a flagging monitoring system for adults with learning disabilities or autism from black and minority ethnic (BME) communities.	Annual reasonable adjustment audits on patient notes randomly chosen within acute Trust; Patient records show any reasonable adjustments required.

Proposed level		Evidence provided		
Red				
Red/amber				
Amber				
Amber/green				
Green				
2.3 Adults with learning disabilities or autism receive high standards of fundamental care		Audit of basic care takes place in all clinical areas- i.e. Essence of Care ; All activities of daily living needs are assessed and effective care plans put in place	Care audits include the views of adults with learning disabilities or autism and their family carers; Nursing and clinical documentation assesses extra support requirements during hospital stays. Staff ask for and use individual health passports.	Qualitative outcomes are defined within contracting processes - e.g. CQIN Board level reporting of nursing metrics includes specific reference to the experience of adults with learning disabilities or autism Specific support requirements and or reasonable adjustments are consistently assessed and delivered for adults with learning disabilities or autism across the Trust. Health passports are used during the hospital stay and updated.
Proposed level		**Evidence provided**		
Red				
Red/amber				
Amber				
Amber/green				
Green				
2.4 Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs.		The Trust has risk assessment processes in place that are completed for vulnerable groups including adults with learning disabilities or autism	Risk assessment takes into account the specific issues for adults with learning disabilities or autism. Patients identified at risk have appropriate care plans to minimise risk of harm.	The Trust has a comprehensive risk dependency and support assessment specifically for adults with learning disabilities or autism. 100% of all adults with learning disabilities or autism are risk assessed; This assessment is used to identify specific additional support requirements. The Trust has an agreement for the funding of additional support requirements

Proposed level		Evidence provided		
Red				
Red/amber				
Amber				
Amber/green				
Green				
2.5 Adults with learning disabilities or autism receive appropriate nutrition and hydration		Safe swallow guidance available for staff, Adults with learning disabilities or autism and family carers are involved in nutrition care planning. Mental Capacity Act principles are considered in PWLD refusing to eat.	People are supported to make food choices according to their individual needs.	National Patient Safety Agency guidance on safe swallow for people with learning disability is incorporated into Trust safe swallow guidance.
Proposed level		**Evidence provided**		
Red				
Red/amber				
Amber				
Amber/green				
Green				
2.6 Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency departments.		Adults with learning disabilities or autism are identified prior to or on admission.	The identification leads to an assessment of need and appropriate referral. Patient records are flagged to show specific requirements and additional needs, including carer needs.	An electronic flagging system is in place across the hospital; This is available to all appropriate staff. Primary care/ GP and adult social care have an information sharing arrangement in place regarding patient identification.

Proposed level		Evidence provided		
Red				
Red/amber				
Amber				
Amber/green				
Green				
2.7 Training and education on understanding the specific needs of people with learning disabilities and autism is provided to <u>all</u> hospital staff.		Learning disability training is regularly available to staff Learning disability, autism and mental capacity act awareness training is included in induction and mandatory updates for some identified staff This training includes Autistic Spectrum Disorder, Profound and Multiple Learning disability, Dual diagnosis, Mental Health and Dementia.	Relent training is part of the LD / autism strategy. Communication with adults with learning disabilities or autism is part of the curriculum on all training levels. Informal and patient specific training is available from the Acute Liaison Nursing service; There is a Learning Disability / Autism Resource file easily available to all staff.	There is a comprehensive training strategy that includes • measurement of outcomes • quality/levels • Target numbers of staff to be trained each year and to what level • Competencies to be achieved All clinical staff receive learning disability, autism and MCA training at induction and have mandatory updates Administration , domestic and other non clinical staff groups all receive basic awareness training There are ward level LD/autism link practitioners who have received extra training in LD issues Adults with learning disabilities or autism and family carers are actively involved in developing the curriculum. Adults with learning disabilities or autism and family carers are actively involved in delivering training;
Proposed level		**Evidence provided**		
Red				
Red/amber				
Amber				
Amber/green				
Green				

3 Pathways	LEVEL 1	LEVEL 2	LEVEL 3
3.1 Adults with learning disabilities or autism attend outpatient appointments and investigations appropriately	Appointment letters are not complex	There is information on appointment letters that gives clear guidance for further information or support for people with learning disabilities.	Planning for appointments take place. Reasonable adjustments are made to make attendance easier. E.g. last appointment Adults with learning disabilities or autism are identified before appointment letters are generated and sent in an accessible format according to the individuals needs.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
3.2 Adults with learning disabilities or autism attend A&E appropriately	Adults with learning disabilities or autism who are repeat attendees to A&E are known and discharged appropriately.	Repeat attendees to A&E are known and discharged appropriately with referrals and support. Preventative and awareness work is done to prevent inappropriate attendances	Processes are in place with community professionals to prevent repeat inappropriate A&E attendances Link work is done with community teams to prevent inappropriate admissions The liaison nurse works with known individuals to prevent regular inappropriate attendance. Data is gathered and used to prevent inappropriate admissions
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			

3.3 Adults with learning disabilities or autism are discharged home in a safe and timely way.	Discharge planning is commenced on admission; The patient and family/carer are involved in the discharge planning process; Risk assessment is completed on discharge and takes into account person centred plans.	Complex discharge planning meetings include the acute liaison nurse, Community Learning Disability Team, carer and, where appropriate, the patient; The Acute Hospital Liaison Nurse is actively involved in discharge planning.	Complex discharges are person centred and there are no delays because of funding disputes or other non-clinical reasons; Readmissions are monitored against the 30 day target Data on delayed discharges is monitored and used to improve average length of stay duration.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
3.4 Women and partners with learning disabilities or autism have a clear pathway for use of maternity services	Adults with learning disabilities or autism are identified through an assessment process in early pregnancy.	Adults with learning disabilities or autism are identified through an assessment process in early pregnancy and all relevant health care professionals are alerted.	Primary care/ GP and adult social care have an information sharing arrangement in place regarding patient identification. Pathways are in place that makes reasonable adjustments for the needs of parents to be with learning disabilities or autism. Birth outcomes are equal to the local population.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			

4 Involvement and representation of people with learning disability and their carers.	LEVEL 1	LEVEL 2	LEVEL 3
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	Adults with learning disabilities or autism and family carers are able to give their views through PALS or patient groups	Adults with learning disabilities or autism and family carers are consulted for particular projects. Adults with learning disabilities or autism and family carers participate in service evaluation A Trust representative attends the local partnership board and takes views back.	Adults with learning disabilities or autism and family carers are fully involved in development of the LD plan and the evaluation of services. Their input drives service change Adults with learning disabilities or autism and family carers are members of the Trust LD steering group .Minutes, information and discussion is in accessible format.
Proposed level		**Evidence provided**	
Red			
Red/amber			
Amber			
Amber/green			
Green			

4.2 Adults with learning disabilities or autism and their family carers are fully involved in preadmission planning, care planning and care delivery	Adults with learning disabilities or autism and family carers have access to a hospital professional to discuss admission needs Protocols are in place to ensure carer's needs are met. Clear Trust protocols for provision of extra nursing support Carers are consulted on specific nursing and communication requirements of the individual;	Adults with learning disabilities or autism and family carers are given a named contact person in the department they are due to be admitted to. Family carers are involved in developing individualised pathways for elective and emergency admissions The Trust consent policy identifies the carers role in decision making if the person consents or lacks capacity;	A comprehensive pre-admission information pack for family carers is readily available from the hospital; A learning disability Liaison Nurse, or designated learning disability / autism lead is involved when information requires further individualising. The liaison nurse consults with adults with learning disabilities or autism and family carers in pre admission and care planning Family carers are routinely involved in case conferences and ward rounds; Carers needs are incorporated into the learning disability policy
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
4.3 People with learning disabilities or autism are represented in the workforce.	People with learning disabilities or autism are volunteers in the Trust	Paid employment of people with learning disabilities or autism is mentioned in the single equality scheme. People with learning disabilities or autism are employed as consultants for specific projects.	The Trust has people with learning disabilities or autism employed in a range of substantive posts There is an education/internship programme that allows internal recruitment of people with learning disabilities or autism and autism into substantive posts. Reasonable adjustments are made to recruitment and employment processes to facilitate easier employment for people with learning disabilities or autism. There is a system for ongoing support of people with learning disabilities or autism in employment.

Proposed level		Evidence provided
Red		
Red/amber		
Amber		
Amber/green		
Green		

5 Information for people with learning disability and their carers.	**LEVEL 1**	**LEVEL 2**	**LEVEL 3**
5.1 People with learning disability autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions	The preadmission booklet includes specific information for people with learning disability.	There is an accessible version of preadmission information available for people with learning disability autism and their family carers and their carers e.g. going into hospital booklet. People with learning disability autism and their family carers can access accessible information about procedures and conditions before admission	Family carers are automatically linked with the liaison nurses prior to admission e.g. in GP referral process for clinical appointments or admissions; The liaison nurse works with the patient and their family carer to provide individualised information prior to admission. Information is available in a range of formats e.g. audio or film

Proposed level		Evidence provided
Red		
Red/amber		
Amber		
Amber/green		
Green		

5.2 All departments have access to a range of	Trusts LD strategy includes guidance on barriers to	The Trust has an Intranet website/shared drive. staff can	The hospital individualises information according to patient needs. All information can be individualised according to need

resources to help in the production of easy read information. These are available to people with a learning disability or autism and family carers.	communication for adults with a learning disability or autism and their family carers. LD / autism training includes; how to develop accessible information. Adults with a learning disability or autism are involved in the development of accessible information across all departments.	access easy read materials and communication resources, Easy Health Website, Surrey Communication book, All departments have access to wide range of resources e.g. Communication aids, Staff photo board etc; Accessible information leaflets on a range of conditions are available or are being developed for more than 50% of departments/clinical topics including medications; Patients can download this information before admission	All patient information that is developed/updated is checked by a committee that has communication expertise. There is evidence that accessible information is being used to consider informed consent to treatment and capacity assessments.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
5.3 People with learning disabilities or autism and family carers have appropriate information to help them make complaints, discuss concerns and give feedback.	There is an appropriate system in place for people with learning disabilities or autism and family carers to complain. Staff can give people with learning disabilities or autism and family carers' complaints and PALS information forms in accessible format.	The Trust has a process for getting feedback from people with learning disabilities or autism and family carers. People with learning disabilities or autism have been involved in the development of accessible PALS, feedback and complaints forms Accessible complaints and PALS forms are on display in all wards, waiting rooms and public spaces.	The hospital has a robust system for monitoring complaints and feedback from people with learning disabilities or autism and family carers. Feedback leads to an action plan The Trust demonstrates measures to ensure that people with learning disabilities or autism and family carers achieve satisfaction from the complaint process**.** PALS department regularly reports to the LD /autism steering group.

Proposed level		Evidence provided
Red		
Red/amber		
Amber		
Amber/green		
Green		

6 Keeping people safe	LEVEL 1	LEVEL 2	LEVEL 3
6.1 The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism.	A system is in place for reporting and recording all deaths and Serious untoward Incidents(SUI's) of people with learning disabilities or autism in hospital;	Hospital systems, protocols and care pathways are in place and demonstrate learning from SUIs Root cause analysis is carried out on incidents.	Learning from SUIs and deaths is shared across all departments and associated agencies; Root cause analysis is carried out on near misses, deaths and Serious Incidents.
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			
6.2 The Trust demonstrates learning from other incidents involving people with learning disability or autism	Trust incident reporting systems allows identification of incidents involving people with learning disability or autism including safeguarding alerts.	All incidents involving people with learning disability or autism are collated and analysed Bi-annual report is produced for the Vulnerable Adult Board or equivalent.	Information gathered and analysed is included in annual LD / autism steering group report and reported at the Trust Clinical Governance Committee or equivalent.
Proposed level	**Evidence provided**		

Red			
Red/amber			
Amber			
Amber/green			
Green			
6.3 The organisation has ways of listening to adults with learning disabilities or autism and their family carers and learns from this	Patient and Carer Surveys are available in accessible format	Trust reports are published on patient experiences; Evidence of listening to patient /carer feedback and changes in practice is available There is a process for referral to Independent mental capacity advocate (IMCA) service and the Trust holds best interest meetings for adults with learning disabilities or autism.	Protocols in place to encourage representation of adults with learning disabilities or autism and their family carers within Trust Boards, hospital committees and forums; Views and interests of adults with learning disabilities or autism and family carers are incorporated into planning and development of health services. Results of satisfaction surveys are used to make improvements in service provision
Proposed level	**Evidence provided**		
Red			
Red/amber			
Amber			
Amber/green			
Green			

2. Validated RAG Levels and Agreed Improvement Plan

Date agreed……

Signed (Trust)…….…… Position……

Signed (Chair of Validation Panel)…….. Position……...

	Proposed level					Agreed level					Agreed improvements and Time frame
	R	R/A	A	A/G	G	R	R/A	A	A/G	G	
1.1 There is clearly identifiable Board and senior management engagement in embedding a learning disability strategy											
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.											
2.1 The Trust employs a registered healthcare practitioner for people 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 Single Equality Scheme and action plan 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											
2.7 Training and education on understanding the specific needs of people with learning disabilities or 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											
3.3 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											
4.1 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											
4.2 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 or 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 learning disability or autism and their family carers											
5.3 People with learning disabilities or autism and family carers have appropriate information to help them complain, discuss concerns and give feedback.											
6.1 Hospital Trusts demonstrate learning from serious incidents, near misses and all deaths of people with learning disability or autism.											
6.2 The Trust demonstrates learning from other incidents involving people with learning disability or autism including											

safeguarding referrals											
6.3 The organisation has ways of listening to people with learning disabilities or autism and their family carers and learns from this.											

8. A FRAMEWORK FOR STAFF DEVELOPMENT

1 Introduction

The NHS requires health care providers to employ staff with the skill mix appropriate to deliver a high quality service to patients in every circumstance (DH 2010d). This Training and Development Framework seeks to support the delivery of safe, high quality care for people with learning disabilities or autism when they come into hospital and to ensure that they receive care and treatment that recognises and is responsive to their individual needs.

The Department of Health Progress Report for the Parliamentary and Health Service Ombudsman and Local Government Ombudsman in response to the recommendations in their *'Six Lives'* report (2010c), highlights eight key areas which make a difference in improving healthcare for people. One of these is staff training where 'there clearly remains a need for further development, creatively delivered to a variety of healthcare staff' (page 36). The 2011/12 NHS Operating Framework specifically mentions the priority to be given to staff training.

The East of England 'Vision for Better Health and Well Being for People with a Learning Disability and their Families 2011-21' sets out proposed aims and commitments for the NHS in the East of England over the next ten years. Access to health services for all people with learning disabilities across the region and the achievement of equivalent health outcomes to the rest of the community are key commitments within the Vision. High quality workforce development and training for all acute hospital staff that come into contact with patients will be required to support this commitment. People with learning disabilities have also told us that it is important that staff in hospitals are trained, so that they can understand what it is like from their point of view and experience.

Training must seek to develop a positive set of values and beliefs about what it means to be an adult with a learning disability or autism. Evidence indicates that health care for this group of people has been negatively influenced by inappropriate attitudes and erroneous beliefs about the value of life lived with a learning disability or autism (Mencap 2007, Parliamentary and Health Service Ombudsman 2009).

An important principle is the inclusion of adults with learning disability or autism and their family carers in the design and delivery of training. Their contribution will enable negative assumptions to be challenged, while encouraging positive, affirmative values and attitudes to be developed.

2. Outcomes to be delivered through this Framework

Improved experiences for people with learning disability or autism and their carers when they come into hospital, resulting in successful investigations, treatment and care.
Improved staff competencies in supporting and caring for adults with learning disability or autism;
Improved decision making processes with adults with learning disability or autism, including assessing for capacity to support decisions about care and treatment;
Improved understanding of the value of a life lived with a learning disability or autism, underpinned by a flexible approach that ensures person centred treatment is as the heart of all aspects of care.

3. Overview of the Framework

The training and development framework is organised around a number of discrete levels, these levels fit within a matrix arranged around core skills and knowledge and comprise:

Level 1 Training:

Aims to raise awareness of adults with a learning disability or autism; identifies them as a vulnerable group and outlines the factors that increase their risks. Awareness raising is the first step towards understanding the needs of this group of individuals.

Level 1 Training Target Audience: At Induction for all staff who have patient contact. At yearly or bi-yearly mandatory updates for all current staff that have patient contact.

Duration: 40 Minutes

Level 2 Training:

This level of training aims to provide a good basic knowledge of learning disability, including how to identify an adult with a learning disability or autism and the skills required to support effective communication. Having a good basic knowledge will increase the ability of staff to deliver good patient centred care and to meet the needs of adults with a learning disability or autism and their carers. Attitudes and beliefs about what it means to have a learning disability or autism are raised through exploration and discussion of patient stories.

Level 2 Training Target Audience: Key staff identified at critical points in the patient journey including Ambulance Personnel; Reception Staff at Accident & Emergency Departments; Patient Flow or Bed Managers; Porters; and Security Staff.

Duration: Three Hours

Level 3 Training:

This is a one day training session. In addition to basic knowledge outlined in Levels 1 & 2, training will provide knowledge around the following: identifying health issues known to be more prevalent in adults with learning disabilities or autism; understanding and meeting physical care needs; knowledge of the role of community health and social care services. Skills include: assessing capacity and making best interest decisions. Insight into the patient experience is provided by adults with learning disability and their family carers.

Level 3 Training Target Audience: All clinical staff in acute hospital.

Duration: Full Day

Level 4 Training:

Training is targeted at Learning Disability Link Practitioners, who will be qualified Nurses, Assistant Practitioners or Senior Health Care Assistants who are ward based and who will have expressed an interest in developing their skills and knowledge in caring for this group of people. A key aim is to equip Learning Disability Link Practitioner with knowledge and skills that can be disseminated across their workplace to drive up standards in care. Target areas for the initial development of the Learning Disability Link role should include Medicine, Surgery and Neurosciences. Norfolk and Norwich University Hospitals NHS Trust have developed a role description for the Learning Disability Link Practitioner and this is included in Appendix 1.

Level 4 Training Target Audience: Qualified Nurses, Senior Health Care Assistants or Assistant Practitioners

4. The Staff Development Framework

Level 1 Training	
Aim:	Raise awareness of adults with learning disability or autism.
Target Audience:	At Induction & Mandatory Sessions: All staff with patient contact
Learning Outcome:	At the end of the session the participants will be able to: ➧ Identify the characteristics associated with having learning disability or autism; ➧ Identify adults with learning disability or autism as vulnerable within an acute hospital setting; ➧ Identify the factors that are known to increase vulnerability in this group of people; ➧ Identify Learning Disability Specialist Nurse as source of information about and support for adults with learning disability or autism.
Why - Evidence Base:	➧ Adults with learning disability or autism are vulnerable in acute hospital settings (DH 2008). ➧ They are more likely to experience discrimination; care is often characterised by problems that undermine personalisation, dignity and safety (DH 2009, RCN 2010). Decisions to treat can be complex and physical care is often poor or inadequate (Mencap 2007). ➧ Problems with communicating and expressing needs and choices; difficulty reporting symptoms and recognition of pain are some of the factors known to increase vulnerability (Mencap 2007, DH 2008, DH 2010a) ➧ Raising awareness is the first step towards understanding the needs of this group of individuals

	and of reducing the likelihood of harm.
Resources and Materials to Support Training	➡ *Safeguarding adults: If you don't do something, who will?* DVD produced by *Nursing and Midwifery Council.* *www.nmc-uk.org/safeguarding* ➡ *Learning Disability Awareness*. Power point Presentation: Queen Elizabeth Hospital Kings Lynn NHS Trust ➡ *Learning Disability and Autism Awareness*: E Learning Package in development: Norfolk and Norwich University Hospitals NHS Foundation Trust
Level 2 Training	
Aim:	Provide knowledge of what it means to have a learning disability or autism including understanding how to identify someone with a learning disability and how to make adjustments to ensure that the person receives individual support to use hospital services.
Target Audience:	Staff groups identified in the care pathway as being critical to implementing reasonable adjustments include:- ➡ Ambulance Personnel; ➡ Accident and Emergency Reception Staff; ➡ Accident and Emergency Triage Nurses; ➡ Porters; ➡ Patient Flow Managers or Bed Managers.
Learning Outcomes:	At the end of the session the participants will be able to: ➡ Identify why people with learning disability or autism are vulnerable in acute hospital settings; ➡ Understand the implications of diagnostic overshadowing; ➡ Understand how to input and use clinical alerts/flags to identify adults with or who may have a learning disability or autism; ➡ Recognise and know how to use patient held information such as the Hospital Passport, Emergency Department Grab Sheets, or Health Action Plans; ➡ Identify the importance of good communication and demonstrate basic communication strategies; ➡ Understand the importance of listening to and engaging with family carers and ensuring that no decision is made without them or the learning disabled adult or adult with autism.
Why – Evidence Base:	➡ Adults with learning disability or autism have difficulty with accessing and using all health services (DH 2008). Health action plans, hospital passports and other patient held information enables access and supports the implementation of reasonable adjustments

	➡ Evidence indicates that commonly symptoms are attributed by acute hospital staff to the learning disability rather than to any underlying health problem (Mencap 2007, DOH 2008, Local Government & the Parliamentary & Health Service Ombudsman 2009). ➡ Hospital systems can be difficult for adults with learning disability and their families to navigate. Good practice recognises the value of being able to identify people with learning disability or autism as they enter and move through acute hospital systems (DH 2008, NHS London 2010, DH 2010c) ➡ Adults with learning disability or autism often require adjustments to be made to help them to undergo investigations and treatment and to receive adequate care (DH 2008, DH 2010b, DH 2010c). ➡ Waiting in clinic areas is known to be very stressful for some adults with learning disability and for adults with autism. Providing quiet areas or giving people first appointments are adjustments that can enable people to have successful consultations, treatment outcomes and positive acute hospital experiences; ➡ Knowledge and understanding of basic communication principles will ensure that interventions remain person centred.
Resources and Materials to support Training	➡ *Accident and Emergency Grab Sheet* – Northamptonshire Health Care NHS Trust & Northamptonshire NHS Primary Care Trust; ➡ *Health Action Plans* - a good example is the Purple Folder used across health and social care services in East and North Herts NHS Trust and West Hertfordshire Hospitals NHS Trust. ➡ *"What if your next patient has a learning disability"* – East Midlands Ambulance Service NHS Trust; ➡ *Communication Symbols for ambulance vehicle staff* – East Midlands Ambulance Service NHS Trust; ➡ *Reducing anxiety and supporting admission to hospital*. A DVD produced by Norfolk and Norwich University Hospitals NHS Foundation Trust.

Level 3 Training	
Aim:	Provide staff with knowledge and skills to support and care for adults with learning disability or autism.
Target Audience:	Training day aimed predominantly at Qualified Nurses, Assistant Practitioners, Health Care Assistants, Allied Health Staff, and Medical Staff but open to all staff that come into contact with patients.

Learning Outcomes:	At the end of the day, participants will be able to: ➡ Identify what learning disability is and is not; identify autism; ➡ Gain an insight into the patient and family experience and understand the importance of listening to and engaging with family and carers; ➡ Identify health conditions known to be more common in adults with learning disability or autism; ➡ Identify people with profound and multiple disabilities as a particularly vulnerable group and recognise the factors that increase their vulnerability ➡ Understand the implications of diagnostic overshadowing; ➡ Demonstrate understanding of the physical care needs of adults with learning disability or autism, and adults with profound and multiple disabilities and discuss strategies for identifying and meeting these; ➡ Identify and use strategies to communicate effectively with people with learning disability ➡ Demonstrate an understanding of decision making, capacity and best interests in the care of people with learning disability or autism: To explore the implementation of the Mental capacity Act for registered and non registered staff ➡ Identify and understand the role of community learning disability health and social care services.
Why – Evidence Base:	➡ Family carers are often experts in understanding the health needs and conditions of their offspring with learning disability or autism (Mansell 2010, DH 2010c). ➡ Certain health conditions are more common in people with learning disability or autism. This group of people often experience difficulties in gaining access to health care and treatment because many health conditions are not recognised (DH 2008, DH 2010a) ➡ Adults with learning disability often experience inadequate physical care; they are more likely to have difficulty with swallowing; with maintaining nutrition and with eating and drinking (Mencap 2007, Local Government & the Parliamentary & Health Service Ombudsman 2009) ➡ Adults with profound and multiple disabilities are known to have substantial, complex health care needs, these include problems with swallowing, postural care, seizure control and detection and management of pain (Mansell 2010, DH 2010a) ➡ Lack of awareness amongst acute hospital health care staff of these issues increases vulnerability (DH 2008). ➡ In addition many adults with learning disability or autism require support to maintain dignity and

	privacy (RCN 2010) • Understanding how to communicate with someone with a learning disability or autism will enable care to be carried out in collaboration with the person; will minimise distress and ensure that dignity is maintained (RCN 2010, NHS London 2010) • The inclusion of adults with learning disability or autism and their family carers in the delivery of training can help to promote positive attitudes and beliefs about living with a learning disability or autism
Resources and Materials to Support Training	Resources to support acquisition of knowledge: • *Describing learning disability*. Introduction to Learning Disability Psychiatry. Cambridge & Peterborough NHS Foundation Trust • *Understanding and recognising … Autistic Spectrum Disorder*. Introduction to Learning Disability Psychiatry. Cambridge & Peterborough NHS Foundation Trust • *Identifying and understanding physical care needs*. Power point presentation: Cambridge University Hospitals NHS Foundation Trust; • *Common health conditions in people with learning disabilities*. Power point presentation: Mid Essex Hospital Services NHS Trust • *The Mental Capacity Act and Consent to Treatment*. Power point presentation: Norfolk and Norwich University Hospitals NHS Trust; Resources to support development of skills: • *Patient Scenarios*. Cambridge University Hospitals NHS Foundation Trust; • *Applying the Mental Capacity Act* – MCA Best Practice Guidelines – Case Studies. • *Lucy's Treatment.* Social Care TV training materials: Social Care Institute for Excellence(SCIE): http://www.scie.org.uk/socialcaretv/default.asp Patient experience: • Role play "My journey" A person with learning disability shares his experiences of health care – Christian Raphael, Matthew Clark and team (see best practice index for contact details.

Level 4 Training	
Aim:	• To develop enhanced knowledge and skills in assessing and managing the needs of adults with learning disability or autism in an acute hospital environment; • To develop practitioners who are able to disseminate knowledge and skills across the workforce. It would be expected that the participant

	would have undergone Level 3 Training.
Targeted at:	➡ Learning Disability Champions who will usually be qualified Nurses, Assistant Practitioners or Senior Health Care Assistants who are ward based or in Accident and Emergency Departments.
Learning Outcomes:	Individuals should be able to: ➡ Demonstrate an ability to identify and anticipate the specific care needs of the adult with a learning disability or autism when they are admitted to the A&E department or ward; ➡ Understand and demonstrate the importance of clear and consistent communication and the need to involve the adult with learning disability or autism in all aspects of care and choice; ➡ Understand that behaviour may often communicate important messages such as pain, distress, or confusion and demonstrate how to respond appropriately; ➡ Understand the importance of listening to and involving family carers and paid carers in planning care and decision making; Share knowledge with and role model skills to other members of acute hospital staff. Learning will take place in the work place, will reflect current available evidence, and will focus on the provision of care and support for an adult with a learning disability or autism across three areas: ➡ assessing, planning and meeting physical health needs; ➡ interacting and communicating with the adult with learning disability or autism and; ➡ understanding and responding to distress in a person with learning disability or autism. ➡ The individual learner will need to consider how they worked in partnership with family carers and or paid carers across each of the areas. ➡ Evidence to support learning would be collected via portfolio and reviewed with an identified supervisor, or alternatively via an action learning set. Ways of accrediting learning will need to be explored.
Resources and Material to Support Training	➡ *Behaviour as Communication*: A Teaching Project for Nursing Care. Cambridge University Hospitals NHS Foundation Trust

5. Norfolk and Norwich University Hospitals Link Practitioner Role Description

Norfolk and Norwich University Hospitals NHS
NHS Foundation Trust

Learning Disabilities/Autism and Safeguarding Vulnerable Adults Link Practitioner Role Description

Role purpose

- To promote and act as a principle point of contact for patients with Learning Disabilities and/or autism (PWLD/A), their families, department staff and the acute liaison nurse

- To act as a resource, disseminate information and be an advocate for patients with PWLD/A that access services in their area.

- To act as a resource to other staff within their unit for safeguarding adults issues.

Key duties and Responsibilities

- To disseminate and cascade updated information about PWLD/A and safeguarding: Ensuring all staff are aware of the vulnerable adult resource folder available on the Trust intranet.

- To contribute towards the area/department compliance with the Equality Act (2010) Raising understanding of what constitutes a reasonable adjustment.

- To encourage the participation and uptake of staff to complete the e learning training packages for safeguarding vulnerable adults and learning disability.

- To develop as required accessible information relevant to their area. To signpost other staff to the resources available to support the development of accessible information e.g photo symbol bank, easy health website.

- To ensure that patient information leaflets are displayed in their area that give information on reporting abuse, PALS and complaints and that easy read versions are also displayed.

- Act as the patients advocate and support colleagues to understand and use the Trust consent policy, Mental Capacity act (2005) and Human Rights act (1998).

- To offer support and advice to relatives and carers using recommendations in the Trust carers policy and learning disability policy.

- To understand barriers to communication and act as a resource to staff for using alternative methods or tools for communication.

- To ensure that PWLD/A have the LD alert code added to the PAS System.

- To assist staff to identify risks for people with a learning disability or autism.

- To have knowledge of the Trust safeguarding policy and signpost staff to appropriate action if they have concerns

Professional responsibilities

- It is expected that nominated link practitioners will keep up to date with developments in learning disability/autism and safeguarding issues in their own clinical area through attendance at link practitioner meetings and through regular mandatory updates.

Role specification

Qualifications 1. Trust employee	Essential
Knowledge and experience 1. Has attended the Trust learning disability study day. 2. Attended the Trust safeguarding vulnerable adult training and mandatory updates 3. Working in the clinical area for one year. 4. Previous experience working with learning disabled or vulnerable people.	Essential Essential Desirable Desirable
Skills and abilities 1. Interest in learning disability and vulnerable adults 2. Enthusiasm for improving services PWLD/A 3. Ability to be creative in supporting reasonable adjustments. 4. Good communication skills 5. Uses the email system to access disseminated information.	Essential Essential Essential Essential Essential
Training and development 1. Regularly attend link practitioner meetings 2. Keeps updated on current developments in learning disabilities and safeguarding	Essential Essential

9. THE ROLE AND ORGANISATIONAL REPORTING STRUCTURE FOR ACUTE HOSPITAL LIAISON NURSES

The Department of Health's Six Lives Progress report (October 2010) reports that *'where progress (has been made by acute hospitals) it is frequently linked to the work of acute liaison staff'* (page 32). As part of the east of England Commissioning Framework 2011/12, each PCT committed to the appointment of a learning disability liaison nurse for each acute hospital in the region. Good progress has been made in this, with 14 out of 17 acute hospital Trusts now having made these appointments. This section makes four recommendations which are aimed to ensure that Trusts are making the best use of the role of the learning disability liaison nurse.

1. Ensure that there is a Trust improvement plan for learning disability and autism, not one solely for the learning disability liaison nurse.

Improving pathways and health outcomes for adults with a learning disability and adults with autism is an issue for the whole hospital Trust, not solely for the liaison nurse.

Liaison nurses have key roles in:

- developing effective care pathways;
- training and capacity building of staff;
- direct intervention and support for those with most complex needs;
- developing resources, e.g. easy read information
- policy and guidance development
- monitoring and reporting on quality and risks

However, these will not in themselves ensure systematic improvements. It is key that all aspects of the Trusts operations, as detailed by this project, are considered through the Quality Assurance Framework (Chapter 7) and an improvement plan drawn up and agreed. Implementation is likely to be through a number of routes and fora, with the learning disability liaison nurse able to contribute their expertise and knowledge to these, as well as through their own lead responsibilities.

2. Ensure that your Learning Disability Liaison Nurse reports to a senior manager with direct access to the Trust Board

Two key aims for a Trust's learning disability and autism improvement plan is to improve the health outcomes for people and, in a potentially high risk environment, manage individual and corporate risk. Learning disability liaison nurses are key change agents in both these areas and need to be embedded into governance structures so that their expertise and feedback on progress and risk is readily and regularly available to senior managers and to the Trust Board.

Currently, the majority of liaison nurses are employed at Band 7, with one nurse at Band 5 and another at Band 8a. There are currently a number of different arrangements of who these nurses report to:

- Directors of nursing

- Deputy directors of nursing
- Patient & public experience director
- Quality and governance director
- Education department lead

It is recommended that learning disability liaison nurses:

- report to a member of the Trust Board, who acts as a Learning Disability and Autism Champion.
- are closely involved in providing regular reports to the Executive Team and Trust Board on progress in the delivery of improvement plans and issues in relation to safety and risk for adults with a learning disability and adults with autism.
- have an appropriate grading for this level of responsibility.

3. Ensure the learning disability liaison nurse post is substantive, clinical and has sufficient capacity

The generally reported experience of recently appointed liaison nurses in the east of England is that once they are in post the work load is much greater than that expected. This may be because:

- the number of people with a learning disability or autism using the hospital is far greater than originally thought or is currently recognised, with very few hospitals currently able to provide an evidenced level of activity (see Chapter 5)
- the intensity and length of engagement with some individuals is greater than expected (linked to potential risks for individuals)
- the range of issues to be addressed is greater than anticipated e.g. improving clinical practice; introducing hospital policies; developing patient and family carer engagement; links with external services

Currently, of 17 acute hospital trusts in the east of England 14 employ clinically qualified learning disability liaison nurses. Of these:

- 10 Trusts employ 1 liaison nurse full time
- 3 Trusts employ 2 liaison nurses part time (in one Trust, these are two matrons who respectively focus on emergency and elective care)
- 1 Trust employs 1 liaison nurse half time.
- 2 acute hospital Trusts in the east of England currently do not employ a learning disability liaison nurse.

Of the 17 Liaison Nurses:

- 13 are on substantive contracts
- 4 are on 6 – 12 month contracts

It is suggested that having half time capacity and / or time limited contracts significantly underestimates the work levels required of liaison nurses and the organisational need for long term inputs and capacity to deliver high quality pathways and outcomes. Coverage of Accident

and Emergency, with its 24/7 delivery of service also need to be included when considering the capacity required.

One Trust has a vulnerable adults lead who is not clinically qualified. This latter approach will restrict the various inputs which can be made to clinical training and practice.

4. Ensure the liaison nurse is employed by the acute hospital Trust

Currently, there are a number of different employment arrangements for learning disability liaison nurses:

- by the acute hospital Trust
- by the learning disability / mental health specialist health provider
- by the local authority (where there are particular partnership arrangements in place).

The experience reported by liaison nurses is that where they are employed outside the acute Trusts they can encounter important limitations in working and contributing effectively:

- a lack of formal reporting arrangements into the acute hospital Trust management and Board structures. Often a 'dotted line' arrangement is in place for meetings and reporting, relying often on individuals rather than organisational structures to ensure these work effectively.
- not being included in acute Trust communications and organisational development
- restrictions or lack of access to hospital patient information systems

It is suggested that employment by the acute hospital Trust will address these difficulties and embed the work of the liaison nurse in the life and work of the Trust.

10. PROTOCOLS, AGREEMENTS AND GUIDANCE TO SUPPORT THE ACUTE HOSPITAL PATHWAYS

1. **Protocol for alerts and reviewing repeat attendances at A&E and appropriate actions.** This should include:
   - Agreement of the definition of 'repeat attendances' e.g. four attendances over a four week period (if not agreed already); balance of severity against frequency.
   - How information systems will identify repeat attendances (if not in place already)
   - The identification of someone who has a learning disability, autism or is vulnerable who is repeatedly attending A&E. To include how someone might be identified if they do not notify staff themselves.
   - Appropriate involvement of and information to the Hospital Learning Disability Liaison Nurse.
   - The identification of the A&E clinician responsible for coordinating a review of the repeat attendances and subsequent plan.
   - Actions if a Hospital Learning Disability Liaison Nurse is not available e.g. weekends, night time.
   - Awareness of possible impact of policies of different agencies e.g. school policy for epilepsy to call an ambulance as a standard protocol to someone having a seizure.
   - Ensuring effective information exchange to GP and community services on discharge

2. **Bed Management Protocols.** These should be reviewed and reasonable adjustments incorporated to include the needs of adults with a learning disability and adults with autism:
   - Continuity of staff from assessment to treatment to discharge or admission, or the introduction of new staff during this process
   - Avoid multiple bed moves
   - Identify and specifically address any risks to continuity of staff and information
   - Ensure the flag which signifies someone has a learning disability or autism is visible to the Bed Manager
   - Transfer of information to avoid the need for repeated questions (includes communication and personal care)
   - If attending Theatre, refer to Protocol for Theatre and Recovery
   - Involving the Hospital Learning Disability Liaison Nurse.

3. **Protocol for Additional Funding and External Staffing.** This should be agreed by Acute Hospital Commissioners, Acute Hospitals and Adult Social Care Commissioners. The Protocol should include:
   - what will constitute additional supports whilst in hospital (people and/or equipment)
   - when additional supports are appropriate
   - management responsibilities for additional staff
   - necessary training and competence levels needed
   - responsibilities for funding.

   This protocol will also be relevant for other groups of patients e.g. people with significant physical care needs or mental ill health

4. Protocol / Pathway for Theatre and Recovery. An example from Mid Essex Hospital NHS Trust:

Nursing staff from the patient's ward should contact the appropriate operating theatre 24 hours in advance (if elective) and as soon as possible in emergencies to discuss any specific patient needs

This information should also be conveyed to the Recovery Room staff

Nursing staff from the patients ward will contact the Acute Pain Team and request a pre operative assessment

Patient to make a pre-operative visit to Recovery room if possible (e.g. elective admission)

Arrange, if possible for the patient to be accompanied to theatre by someone known to him or her

PREPARATION FOR THEATRE

The following issues should be discussed during the pre-op/pre assessment visit between patient, nursing staff and main carer:

1. The patient's previous experience of anaesthesia and surgery
2. Behavioural patterns during recovery of anaesthetic
3. The patients communication needs

The main carer, parent or guardian may wish to accompany the patient to the anaesthetic room and/or be in attendance during recovery

The ward nurse should remain in the anaesthetic room to provide continuity

RECOVERY

Once the procedure is complete the recovery nursing staff should contact the ward to notify the main carer that the procedure is complete. If necessary the main carer may be present in the recovery room.

Where possible the patient should be escorted back to the ward by a recovery nurse or ward nurse who is known to them

Community Disabilities Team can offer support and advice to the Theatre and Recovery Room staff

5. **Guidance on the role of family carers whilst someone is in hospital.** This should be agreed by Acute Hospital Commissioners and Acute Hospitals, using the views of family carers and people with a learning disability. The guidance can be included in the Hospital Trust's Carers Policy if this is in place.

   Queen Elizabeth Hospital, Kings Lynn has a comprehensive Carer's Policy which, without specifying particular patient groups, provides for the key issues for family carers of adults with a learning disability or autism

6. **Agreement on Data Exchange/Sharing.** This should be agreed by the Acute Hospital Commissioner and the Acute Hospital to enable basic data to be exchanged which enables the acute hospital to have a data base of people with a learning disability based on GP learning disability registers. The agreement must address Caldicott requirements.

   Hertfordshire PCT and West Hertfordshire Hospital Trusts have finalised such an agreement for a one off exchange of data. Given that the GP Learning Disability Registers apply to people aged 18+, a refresh of the data may be required annually.

7. **Agreement on Emergency Cards; Hospital Passports; and Health Action Plans.** Each local area needs agreement and clarity about the titles and the information to be included in:
   - A card with emergency information.
   - Hospital Passport
   - Health Action Plan

   Agreement will be most effective if these are agreed by Health Commissioners; Acute Hospital Trusts; Learning Disability / Mental Health Trust; Adult Social Care; Housing agencies.

11. INDEX OF GOOD PRACTICE IN THE EAST OF ENGLAND

This QIPP project has revealed a range of good practice in the east of England in relation to acute hospital care for adults with a learning disability and adults with autism. This index collates the good practice which has been identified, and also some nationally available information.

It is important to note that good practice is not automatically transferrable from one acute hospital to another setting. These examples are given as a basis for each hospital to make them relevant and deliverable in their own setting. Neither does the good practice reported here represent the 'final word' in practice. Good practice will need to be constantly developed to reflect new developments and new knowledge. Neither will those delivering this best practice necessarily be satisfied with it. They are likely to be aware of short falls and how they need to be addressed. Most important is the organisations' attitudes and values in seeking to constantly improve practice and outcomes for people.

This index gives the headline for each good practice example. Further detail is not given both for the sake of brevity in this document, and because over time the good practice may have moved on. The primary contact for each hospital is the learning disability liaison nurse, with contact details given at the end of this chapter. Where the contact is not the liaison nurse, those details are given in the text.

The good practice is outlined in relation to relevant chapters of the report.

Subscribing to the **UK learning disability network** will give access to a range of resources and on line discussion including the **access to acute network** the forum in which health and social care professionals share issues around access to acute services. This is hosted by the Foundation for People with Learning Disabilities: http://www.ldhealthnetwork.org.uk. The network is facilitated by Janet Cobb who can be contacted at: jcobb@fpld.org.uk

The Learning Disability Public Health Observatory 'Improving Health and Lives' is also a source of good practice nationally: http://www.improvinghealthandlives.org.uk/

An east of England Network of Learning Disability Liaison Nurses is convened by Shoenagh Mackay, Learning Disability Nurse Advisor at Basildon and Thurrock University Hospital as part of a Regional Innovation Fund project. Shoenagh's e-mail is: shoenah.mackay@btuh.nhs.uk

1. Patient pathways for adults with a learning disability and adults with autism

1. Bedford ambulance service: employs 'Emergency Practitioners'' as first responders. These are highly skilled and excellent at face to face emergency work for people with a learning disability. Contact: Suzannah Lee, Trust Lead for Equality, Diversity and Human Rights, East of England Ambulance Service NHS Trust: suzannah.lee@eastamb.nhs.uk

2. Basildon and Thurrock Hospital: deliver specific training for Ambulance Service staff on working with people with a learning disability.

3. South Essex: have introduced an Emergency Card for people to use: the '999 Card'

4. Bedford Hospital: has developed a 'Patient Safety Card'

5. Basildon and Thurrock Hospital: use Traffic Light Sheets to record key health needs and key risks for someone.

6. Luton and Dunstable Hospital: have developed
   - a 'Grab Sheet' for A&E reception staff
   - a Learning Disability Discharge Summary sheet
   - All About Me information for pre admission planning
   - a 'Grab Sheet' for A&E and ward staff
   - A discharge Sheet
   - A Learning Disabilities Intranet site
   - 'Your Next Patient' (has a learning disability) leaflet

7. Hertfordshire hospitals: use a Purple Dot and Purple Folder system. The folder accompanies the person and is used to hold all key documents:
   - Emergency 'grab' sheet
   - Health Action Plan
   - 'About Me' – a health overview
   - Discharge summaries
   - A checklist of the person's involvement and mental capacity guidance

   A dvd is used to explain the system to acute staff, GPs, patients and family carers, paid support staff.

8. Hinchingbrooke Hospital: have developed
   - 'This is Me' incorporating both a patient passport and a traffic light overview of someone's health needs

9. Several local films have been made to support people with a learning disability or autism coming into hospital

   - Ipswich Hospital: a DVD giving information about using their services.
   - Through Barry's eyes - Hertfordshire PCT
   - Top ten tips for coming into hospital - Norfolk & Norwich University Hospital

10. Mid Essex Hospital have an agreed Protocol for Theatre and Recovery

11. Queen Elizabeth Hospital, Kings Lynn has a comprehensive Carer's Policy which, without specifying particular patient groups, provides for the key issues for family carers of adults with a learning disability or autism

12. The Easy Health web site has a wide variety of easy read materials for people with a learning disability and for professionals in relation to better health and good healthcare: www.easyhealth.org

Particularly relevant are examples of:

- A hospital passport: http://www.easyhealth.org.uk/sites/easyhealth.org.uk/files/hospital_passport_0.pdf
- A Traffic Light Assessment form: http://www.easyhealth.org.uk/sites/easyhealth.org.uk/files/traffic_light_assessment_form_0.pdf

2. Guidance for effective alert and information systems to deliver and monitor improved quality and cost savings

1. A Caldicott Agreement to exchange data:

Hertfordshire PCT and West Hertfordshire Hospital Trusts have finalised such an agreement for a one off exchange of data. Given that the GP Learning Disability Registers apply to people with a learning disability aged 18+, a refresh of the data may be required annually.

Contact: Sarah Damms, Joint Learning Disability / Mental Health Commissioner, Hertfordshire County Council Sarah.Damms@hertscc.gov.uk

2. Physical flagging system:

- Hertfordshire hospitals use a Purple Dot and Folder system. Purple dots are placed on ward boards and also in bedside locations so that everyone working face to face with the person is alerted to the need for appropriate and reasonable adjustments. A purple coloured folder accompanies the person and is used to hold all key documents (see above)

- Norfolk & Norwich University Hospital: use a specific wrist band

3. A Quality Assurance Framework with a model for self assessment and an agreed improvement plan

Involvement of adults with a learning disability and adults with autism and family carers in reviewing hospital services:

1. Luton and Dunstable Hospital:

- A quarterly Learning Disability Patient Group (experience) meeting, which feeds back to PALS and to the Trust's Equalities Committee
- Bi Monthly Learning Disabilities Task Group – currently focussing on Mencap's Getting it Right Charter, and Six Lives. The group consists of a variety of stakeholder's inc parents, carers, pwld, providers, senior hosp managers (inc Trust Board Execs) and the LD Liaison Nurse.

2. NHS Luton: are developing a DVD with the family of a young man with Learning Disabilities who died in hospital that gives the family's experiences of care in hospital. Copies will be available from Simon Pattison, NHS Luton: Simon.Pattison@luton-pct.nhs.uk
3. Norfolk & Norwich University Hospital :

4. Basildon and Thurrock University Hospital:
- 'Tell it to the team' – a group of service users to give the hospital the views of people with a learning disability about its services
- A family carers support group call 'many disciplines one aim'

5. Cambridge University Hospitals:

6. Hinchingbrooke Hospital: have drawn together patient/carer stories based on a satisfaction questionnaire which inform their plans for improvement

7. Hertfordshire Hospitals: people with a learning disability contribute to training in the hospital

4. A Staff Development Framework

- *Safeguarding adults: If you don't do something, who will?:* DVD produced by *Nursing and Midwifery Council.* *www.nmc-uk.org/safeguarding*

- *Learning Disability Awareness*. Power point Presentation: Queen Elizabeth Hospital Kings Lynn NHS Trust

- *Learning Disability and Autism Awareness*: an E Learning Package in development: Norfolk and Norwich University Hospitals NHS Foundation Trust

- *Accident and Emergency Grab Sheet* – Northamptonshire Health Care NHS Trust & Northamptonshire NHS Primary Care Trust;

- *Health Action Plans* - Purple Folder used across health and social care services in East and North Herts NHS Trust and West Hertfordshire Hospitals NHS Trust.

- *"What if your next patient has a learning disability"* – East Midlands Ambulance Service NHS Trust. Contact: Suzannah Lee, Trust Lead for Equality, Diversity and Human Rights, East of England Ambulance Service NHS Trust: suzannah.lee@eastamb.nhs.uk

- *Communication Symbols for ambulance vehicle staff* – East Midlands Ambulance Service NHS Trust. Contact as above

- *Reducing anxiety and supporting admission to hospital*. A DVD produced by Norfolk and Norwich University Hospitals NHS Foundation Trust.

- *Describing learning disability*. Introduction to Learning Disability Psychiatry. Cambridge & Peterborough NHS Foundation Trust: used for training medical students and GPs. Contact: Dr Asif Zia Consultant Psychiatrist Consultant Psychiatrist and Clinical Director: asif.zia@cpft.nhs.uk

- *Understanding and recognising … Autistic Spectrum Disorder*. Introduction to Learning Disability Psychiatry. Cambridge & Peterborough NHS Foundation Trust. Contact as above

- *Identifying and understanding physical care needs*. Power point presentation: Cambridge University Hospitals NHS Foundation Trust;

- *Common health conditions in people with learning disabilities*. Power point presentation: Mid Essex Hospital Services NHS Trust

- *The Mental Capacity Act and Consent to Treatment*. Power point presentation: Norfolk and Norwich University Hospitals NHS Trust;

- *Patient Scenarios*. Cambridge University Hospitals NHS Foundation Trust;

- *Applying the Mental Capacity Act* – MCA Best Practice Guidelines – Case Studies.

Patient experience:

- Role play "My journey" A person with learning disability shares his experiences of health care – Christian Raphael, Matthew Clark and team (contact is through Cambridge University Hospitals – see below)

- Experiences of using hospital services: Luton and Dunstable Hospital

- *Behaviour as Communication*: A Teaching Project for Nursing Care. Cambridge University Hospitals NHS Foundation Trust

5. Acute Hospital Liaison Nurses

Bedford Hospital NHS Trust **Nikki Keer** nichola.keer@sept.nhs.uk
Luton and Dunstable NHS Foundation Trust **Ilona Brunzel** Ilona.Brunzel@ldh.nhs.uk
Cambridge University Hospitals NHS Foundation Trust **Karen Thomson** karen.thomson@addenbrooks.nhs.uk
Hinchingbrooke Hospital NHS Trust **Cheryl Smith** Cheryl.Smith@hinchingbrooke.nhs.uk
James Paget University Hospitals NHS Foundation Trust **Rebecca Crossley** rebecca.crossley@jpajet.nhs.uk
West Herts NHS Hospital Trust **Shirley Dayton** Shirley.dayton@hertscc.gov.uk
East and North Herts NHS Hospital Trust

Louise Jenkins (also LD Palliative care lead) Louise.Jenkins@hertscc.gov.uk **Tracey Logan** Tracey.Logan@hertscc.gov.uk **Frank Garvey** – Strategic Liaison Nurse for Learning Disabilities – frank.garvey@hertscc.gov.uk
Ipswich NHS Hospital Trust **Sally Ryan** sally.ryan@ipswichhospital.nhs.uk
West Suffolk NHS Hospital Trust
Norfolk & Norwich University Hospitals NHS Foundation Trust **Tristan Johnson** tristan.johnson@nnuh.nhs.uk **Stevie Read** stephanie.read@nnuh.nhs.uk
Queen Elizabeth Hospital NHS Foundation Trust **Maria Cox** Maria.Cox@qehkl.nhs.uk
Basildon and Thurrock University Hospitals NHS Foundation Trust **Shoenagh Mackay** shoenah.mackay@btuh.nhs.uk
Southend University Hospital NHS Foundation Trust
Colchester Hospital University NHS Foundation Trust **Mike Pearce** michael.pearce@northeastessex.nhs.uk
Mid Essex NHS Hospital Trust **Sandra Morton Nance** Sandra.MortonNance@meht.nhs.uk
Princess Alexandra NHS Hospital Trust **Carol Austin** carol.austin@pah.nhs.uk)
Peterborough and Stamford Hospitals NHS Foundation Trust Contact: **Toni Tuthill** Antoinette.Tuthill@pbh-tr.nhs.uk

APPENDIX 1: MEMBERSHIP OF THE PROJECT BOARD AND CONTRIBUTORS

Project Board

Angela Thompson, Deputy Chief Nurse, Addenbrookes Hospital, Cambridge

Gerry Toplis, NHS East of England Project Lead, Learning Disability

Dr Asif Zia, Consultant Psychiatrist and Clinical Director, Cambridge and Peterborough NHS Foundation Trust

Dr Ahmed Mayet, GP, Mid Essex

Helen Daly, Family Carer

Vicki Raphael, Family Carer

Derrick Mortimer, Head of Acute and Specialised Commissioning, NHS Luton

Sarah Damms, Learning Disability Commissioning Manager, Hertfordshire Joint Commissioning Team

Tristan Johnson, Learning Disability Liaison Nurse, Norfolk and Norwich University Hospitals NHS Foundation Trust

Shoenagh Mackay, Nurse Advisor- Learning Disabilities, Basildon and Thurrock University Hospitals NHS Foundation Trust

Stevie Read, Practice Development Nurse & Project SEARCH liaison, Norfolk and Norwich University Hospitals NHS Foundation Trust

Karen Thomson, Learning Disability Specialist Nurse, Cambridge University Hospitals NHS Foundation Trust

Maureen Begley, East of England Dementia Programme Manager

Pauline Milne, Deputy Head of Education & Development, East of England Multiprofessional Deanery

Fiona McMillan-Shields, Mental Health / Learning Disability QIPP Programme Manager, NHS East of England

Tom Johnson, Project Manager, NHS East of England

Contributors to the Project

Cambridgeshire High Support Needs Committee

VoiceAbility, Cambridge: Adult Learning Disability Parliament

ACE: Suffolk People First

Luton and Dunstable NHS Foundation Trust Hospital

Cambridge University Hospitals NHS Foundation Trust

Colchester Hospital University NHS Foundation Trust

East and North Herts NHS Trust

West Hertfordshire Hospitals NHS Trust

Hinchingbrooke Health Care NHS Trust

Ipswich Hospital NHS Trust

Mid Essex Hospital Services NHS Trust

NHS East of England Multi-professional Deanery

Norfolk and Norwich University Hospitals NHS Foundation Trust

Princess Alexandra Hospital NHS Trust

Queen Elizabeth Hospital Kings Lynn NHS Trust

James Paget University Hospital

Basildon and Thurrock University Hospitals NHS Foundation Trust

APPENDIX 2: GUIDANCE ON THE EQUALITY ACT 2010 AND MAKING REASONABLE ADJUSTMENTS

The Equality Act 2010 applies to every organisation that provides goods facilities or services to the public.

This law requires these organisations to make reasonable adjustments to alleviate or remove the effects off substantial disadvantage to disabled people.

It means doing things differently if the usual way would substantially disadvantage them. Or providing additional services or equipment to overcome this disadvantage.

Acute hospitals should have considered the needs of disabled people in their facilities planning and single equality scheme. The Department of Health published the following Guidance for NHS organisations in creating a Single Equality Scheme which includes the needs of people with a learning disability. It is equally applicable to meeting the needs of people with autism:

Equal access? : A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109751.pdf

Acute Hospitals are strongly advised to use this Guidance to review their Single Equality Schemes and considering the reasonable adjustments required for adults with a learning disability and adults with autism.

As examples, core considerations for adults with a learning disability or autism in hospital may be around:

- Level of communication and understanding
  - Reading ability
  - Need for alternative communication methods e.g. British Sign Language
  - Ability to understand symbols and or pictures
  - Verbal ability
  - Ability to store and retain information
  - Anxiety and/or phobia
  - Mental capacity
  - Ability to communicate pain or symptoms
- Behaviour
  - Danger or aggression to self or others
  - Level of support required and by whom.
  - Level of ability to wait or cooperate with treatment/interventions
- Physical ability
  - Sensory issues
  - Level of mobility or risk of falls
  - Ability to maintain own nutrition and hydration
  - Hygiene and physical care needs

APPENDIX 3: BIBLIOGRAPHY: KEY POLICIES AND DOCUMENTS

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- Disability Rights Commission (2006): *Equal Treatment: Closing the Gap: Physical health inequalities experienced by people with learning disabilities and / or mental health Problems*
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