The Management of Patients with Learning Disabilities and Autism Guideline

Document Control:

Document Author: Rebecca Crossley Learning Disability Liaison Nurse (LDLN)
Document Owner: Director Of nursing
Electronic File Name: Learning Disability and Autism
Document Type: Operational Guideline
Stakeholder Consultation: Reader Panel (as described within this document)
Approval Level: Divisional Manager/Department Head
Approval Body: Divisional Manager/Department Head

Version Number: 1
Version Issue Date: May 2012
Reference Number: GUI/TWD/RC/3105/01
Effective Date: May 2012
Review Frequency: Three Yearly
Method of Dissemination: Intranet
For Use By: All Staff in JPUHFT

Version History:

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Emergency Admission

A person with a learning disability and or Autism presents at A & E/EADU in an emergency situation. Reasonable adjustments need to be considered at every stage in the process.

Triage the Patient
The nurse will ensure patient’s safety and deal with immediate health care need. The triage process does not necessarily have to happen in A& E
Is there a family member/carer with the patient?

Yes
Gather all relevant information. Complete Specialist Assessment Form or attach ‘Hospital Passport’ if patient has one with them.

No
Identify the main carer/guardian and contact as soon as possible.

Explain treatment options/ procedures, attempt to seek easy read information accessed via trust intranet under ‘Learning Disability’. Gain informed consent.
If patient is unable to give informed consent or you question their ability refer to Mental Capacity Act 2005

Identify Lead Consultant for primary healthcare need

Treat

Is the patient going to be admitted?

Yes
Advise receiving ward of any potential additional care needs or reasonable adjustments that the patient may require as a result of their learning disability, additional nursing resources may be required.

No
Is patient to be referred for an Out patient appointment?

Yes
Admit patient: Refer to Patients ‘My Health Record’ or ‘hospital passport’ – Follow Admission Care Pathway
For advice and guidance Contact: Learning Disabilities/autism Liaison service. Ext 3732 Inform clinical site team

No
Refer to flow chart for Out-Patient attendance, on Trust Intranet
Allow extra time to explain any aftercare i.e. accessible information

Discharge
Care of a Patient with a Learning Disability and or Autism in the Acute Hospital

**Out-Patients**

If Learning Disability is identified on referral letter from G.P
Place on respective waiting list
Send additional letter in easy read, also request patient bring their Health Passport (Available on intranet tbc)

If Choose and Book is used then appropriate appointment time should have been requested.
(if possible don't recommend this method as it can be more difficult)

Waiting list team to contact Out-patients Manager.
If an identified need is highlighted in the referral letter, ensure it is detailed on patients file i.e. hoist required, quiet waiting area, bleep needed...

At appointment patient and or carer to give completed 'Hospital Passport' to outpatient staff.
If patient does not have one staff will offer a blank one to be completed by patient \ carer

Is the patient going to be admitted?

Yes

Patient to be given full explanation of additional tests or investigations
Use easy read leaflets \ photo stories if possible

No

Ensure SAF is completed and detailed handover

Follow up appointment given?
Ensure written down on card with date time month separately
1pm (afternoon) 2 May 2012

Clinic flexibility
To avoid added distress for the patient, It is worth considering changing the patients clinic time to avoid busy, waiting rooms and late running clinics. Quite rooms should be available.

Patient discharged
Care of a Patient with a Learning Disability and or Autism in the Acute Hospital

Planned Admission

For all patients with a learning disability and or Autism wherever possible should have visited the ward prior to admission, with opportunity to take pictures and meet staff, who might be caring for them. Areas of reasonable adjustments should start to be considered.

If appropriate and carers available consider start Rapid Risk Assessment offer leaflets in 'easy read' – via Learning Disabilities Internet page. Allow patient and their carers chance ask question ensure the patient is clear about any expectation i.e. no food after X time, to stop medication, give patient information in easy read. – via Learning Disabilities internet page or Comms dept.

On arrival ensure patient and carers are shown around the ward, and the ward timetable is explained. Ensure that Rapid Risk Assessment is completed with carers support ask for hospital Passport. Discuss with the patient the plan of care, what is expected and when, ensuring the patient understands. Ensure consent has been discussed and conduct MCA assessment if required.

MEDICATIONS

Specific attention should be given to the patient's medication regime including preparation, times and methods of administration; these may have been tailored to the individuals needs and should continue while in hospital.

PROCEDURE & STAY

- Use patients Hospital Passport if available
- Ensure the patient has had the procedure explained using which means most appropriate i.e. photos, drawing etc
- Ensure the consent process has been followed, consider best interest and follow appropriate assessments
- Follow care plans and routines from home where ever possible
- Keep staff same on shifts wherever possible for patient continuity
- Identify support from family and carers
- Consider if carer should support patient to theatre (please refer to theatre pathway
- Ensure standard pain management pathways are followed use Pain rating scale as needed
- Consider support from L.D Liaison Nurse

DISCHARGE PLANNING

- Consideration needs to be given to the appropriateness of the discharge – have the patients needs changed? – is the home environment best placed to met their patients
- Discharge planning should be discussed at time of admission.
- Contact complex discharge team and Liaison Nurse
1.0 INTRODUCTION

The Trust is committed to providing a responsive service that recognises the needs of those patients who may be disadvantaged in accessing care and treatment due to disability or other health inequalities.

In 2001 the government set out a strategy, Valuing People: A New Strategy for Learning Disability for the 21st Century, which requires that public bodies treat people with learning disabilities as individuals, with respect for their dignity (HSC 2001). This was followed up by Valuing people now 2009 which showed little progress.

The Disability Discrimination Act 1995 now the Equality Act 2010 makes it unlawful for service providers to treat disabled people less favourably for a reason relating to their disability. Equality for people with disabilities may require the organisation to make reasonable adjustments to its service to accommodate the special needs of those with disabilities as per the Autism Act 2010 and Equality Act 2010.

The Local Government Ombudsman in his report entitled Six Lives: the provision of public services to people with learning disabilities (House of Commons: 2009) Six lives progress report 2010 and Mencap in its three reports, Treat me Right (2004), Death by Indifference (2007), all highlight that people with a learning disability experience inequalities in access to health care and may receive health care that is unsafe, inadequate and inappropriate to their needs.

This policy sets out the standards of service that the Trust is committed to delivering to address such inequalities.

1.1 Background

Several national documents and investigations have highlighted the issues faced by people with learning disabilities (PWLD) when accessing acute services. The Disability Discrimination Act 2005 now Equality Act 2010 makes it unlawful for service providers to discriminate against PWLD. The Equality Act and Autism Act require organisations to make reasonable adjustments to accommodate their specific or additional support needs.

Mencap reported the tragic deaths of six individuals during their hospital stay (“Death by Indifference” 2007). This report highlighted the need for improved services and care for PWLD in acute hospitals.

In 2008 Sir Jonathon Michael carried out an independent inquiry into access to healthcare for PWLD (Healthcare for All: 2008). It made specific recommendations to acute hospitals on the best practice for care for PWLD.

In 2009 the Ombudsman investigated the deaths of individuals in the Mencap report (Six Lives: The provision of public services to people with learning disabilities: 2009).

The Care Quality Commission (CQC) qualified these reports by setting specific indicators for acute and specialist trusts. All NHS Trusts will be inspected and measured against these. (Indicator’s on access to healthcare for PWLD 2009/2010). Monitor also has similar indicators which can be viewed.

1.2 Purpose

PWLD and/or Autism have the right to the same level of medical and nursing care as that of the general population. However they have specific needs which must be addressed. Evidence shows that health needs of PWLD are greater than that of the...
general population as a whole and that PWLD face several key issues when accessing the services of acute hospitals (valuing people DOH 2001 & 2007) Death by Indifference 74 deaths and counting (Mencap 2012)

- Patient Safety
- Communication
- Staff attitudes, understanding and awareness of their needs
- Consent/capacity issues
- Information in accessible format on treatment options, complaints procedures and appointments
- Inequitable service delivery that does not take into account their disability and make reasonable adjustments
- Issues around safe transfers of care i.e. admission and discharge.
- Increasing need to use maternity services

Trust Values:
This policy is inline with the Trust’s values of putting patients first, aiming to get it right, recognising that everybody counts and doing everything openly and honestly. The policy incorporates these values throughout and an Equality Impact Assessment is completed to ensure this has occurred.

1.3 Scope
All staff groups within the trust have responsibility to ensuring patients with learning disabilities and autism have their needs met. A person centred approach should be adopted at all times.

1.4 Principle Legislation or Guidance Referenced


3 Department of Health (2001) Valuing People

4 Department of Health (2007) Valuing People Now

5 Michael J (2008) Healthcare for all

6 Mencap (2007) Death by indifference


8 Mental Capacity Act 2005

9 Mencap Death By Indifference 74 Deaths and Counting (April 2012)

10 *Six Lives: the provision of public services to people with learning disabilities* (House of Commons: 2009)

11 Six lives progress report 2010

12 Autism Act 2010

13 Equality Act 2010

14 Disability Discrimination Act 2005

Title: The Management of Patients with Learning Disabilities and Autism
Author: Rebecca Crossley Learning Disability Liaison Nurse (LDLN)
Issue: May 2012 Next Review: May 2015
Ref: GUI/TWD/RC/3105/01
1.5 **Standard Supported**

CQC


EOE VISION [http://www.eoe.nhs.uk/learningdisability](http://www.eoe.nhs.uk/learningdisability)

Autism NICE Guidelines DRAFT

EOE Self-Assessment

1.6 **Reader Panel**

The following formed the Reader Panel that reviewed and endorsed this document:

<table>
<thead>
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<th>Post Title</th>
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<tr>
<td>Post 1  Medical Director - Mr John Studley</td>
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<tr>
<td>Post 2  Director of Nursing - Tina Cookson</td>
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<td>Post 3  Deputy Director of Nursing - Julia Hunt</td>
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<td>Post 4  Matrons Group Palliative Care &amp; End of Life – Dawn Taylor</td>
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<td>Post 5  Matrons Group Elective Division – Tracey Bitters</td>
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<td>Post 6  Matrons Group FADS Gynaecology – Angela Wakeley</td>
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<td>Post 7  Matrons Group Emergency Division – Sonia Cole</td>
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<td>Post 8  Matrons Group Theatres – Debra Conner</td>
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<td>Post 9  Matrons Group Deputy Director of Nursing – Jacky Copping</td>
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<td>Post 10 Matrons Group Head of Education &amp; Practice Development – Sharon Crowle</td>
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<td>Post 11 Matrons Group Hospital at Night &amp; Site Services – Anne Daine</td>
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<tr>
<td>Post 12 Matrons Group Acting Matron FADS Paediatrics WD 10 – Justine Goodwin</td>
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<td>Post 13 Newberry Clinic – Tracy Mclean</td>
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<td>Post 14 Matrons Group Infection Control – Linda Hawtin</td>
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<td>Post 15 Matrons Group Emergency Division – Jan Mckirdy</td>
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<td>Post 16 Matrons Group Elective Division – Sarah Morris</td>
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<td>Post 17 Matrons Group FADS Head of Midwifery Services – Carol Mutton</td>
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<td>Post 18 Matrons Group Emergency Division – Sarah Plume</td>
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<td>Post 19 Matrons Group Emergency Division – Rosemary Smalley</td>
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<td>Post 20 Learning Disability Team Manager – Steve Niece</td>
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<td>Post 21 Learning Disability Team Manager – Ita Wentworth-wood</td>
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1.7 **Trust Values**

This Procedure conforms to the Trust’s values of putting patients first, aiming to get it right, recognising that everybody counts and doing everything openly and honestly.

1.8 **Glossary**

The following terms and abbreviations have been used within this Guideline:

<table>
<thead>
<tr>
<th>Term</th>
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<tr>
<td>LDLN</td>
<td>Learning Disability Liaison Nurse</td>
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<td>PWLD</td>
<td>People with Learning Disabilities</td>
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<td>CQC</td>
<td>Care quality commission</td>
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<td>DDA</td>
<td>Disability Discrimination Act</td>
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<td>LD</td>
<td>Learning Disabilities</td>
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<tr>
<td>LDA</td>
<td>Learning Disability and Autism</td>
</tr>
<tr>
<td>EOE</td>
<td>East Of England</td>
</tr>
<tr>
<td>FADS</td>
<td>Family &amp; Diagnostic Services Division</td>
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1.9 Distribution Control

Printed copies of this document should be considered out of date. The most up to date version is available from the Trust Intranet.
2.0 GUIDE FOR PRACTICE

All Employees must adopt a person centred approach to meeting the needs of the patient with a learning disability. Ensure they are at the centre of all decisions to be made either administrative or clinical.

Employees must recognise that people with learning disabilities and/or Autism may have particular needs related to their disability and that consideration must be given to meeting those needs when delivering other services using reasonable adjustments and requesting support from Learning Disability Liaison Nurse (LDLN) as appropriate. Principles of MCA must be adhered to at all times.

People with a learning disability will be supported to exercise their capacity to make decisions and to consent to treatment where the clinician determines that they have the capacity to do so. In those circumstances where the clinician determines that the person is unable to exercise full capacity to consent to treatment, every effort will be made to ensure that the person understands in simple terms the risks and benefits associated with that treatment.

All Staff are to adopt a person centred approach to care

Five Statutory Principles
The Act is underpinned by five principles, which are contained within the act and explained in the Mental Capacity Act code of practice:

- a presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- the right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions
- that individuals must retain the right to make what might be seen as eccentric or unwise decisions
- best interests - anything done for or on behalf of people without capacity must be in their best interests
- Least restrictive intervention - anything done for or on behalf of people without capacity should be an option that is less restrictive of their basic - as long as it is still in their best interests.

Learning Disability Steering Group

The Learning Disability Steering Group will provide a forum to steer the recommendations from valuing people and other relevant policy and guidance documents. (Terms of reference please see appendix 1)

Undertake responsibility for overseeing the development of services within the Trust to meet the needs of people with learning disabilities and their families and carers.
Develop policies and resources and initiate programmes of training to ensure that staff has the guidance, knowledge and skills required to provide care and treatment that meets the needs of people with learning disabilities.

Coordinate a network of learning disability link practitioners throughout the organisation who will act as a resource to colleagues and take on the responsibility of being an advocate to support a person with learning disability accessing services within that department. The Link Practitioners will be responsible for developing resources in their area. (See appendix 2)

To develop links with local carer, advocacy groups to enable them to influence service development.

Set up audit systems to measure the quality of services provided

2.1 Training

The Trust will support the provision of training to enable staff to understand the additional needs that people with a learning disability and or Autism may have and to develop the knowledge and skills to be able to provide a responsive service that meets those needs.

As per recommendations set out in the Michaels report (2008), Autism Act 2010, NHS EOE 2010-2021, ensure that curricula include mandatory training in Learning disabilities and/or Autism and involves people with learning disabilities/Autism and their carers.

2.2 Guideline Objectives

The objective of the Guideline is to:

Ensure comparative health outcomes for people with learning disabilities and Autism. The Trust recognises that people with a learning disability may have difficulty in understanding information presented only as written text and will endeavour to provide a range of information in easy-read formats or other media to promote understanding and to enable people with a learning disability to make informed choices about their care and treatment as per CQC Level indicator along with government directives and policy guidance.

All departments and units will be encouraged to develop easy read information in a range of formats including pictorial pathways, letters and the use of other media to promote understanding of the proposed care and treatment pathway and to enable the PWLD to make informed choices about their treatments.

In short the objective of the Policy is to:

To ensure that acute services provided to PWLD are equitable and safe.

To provide a responsive service to meet PWLD’s individual needs and that makes reasonable adjustments for their disability.

To offer guidance and support to hospital staff when caring for PWLD

To set out the standards to demonstrate the Trusts commitment to address the health inequalities that this patient group face.
2.3 Guideline Definitions
Please see Glossary of terms.

2.4 Support for this Guideline

Acute Liaison Nurse for people with learning disabilities: Rebecca Crossley:
01493 453732 Bleep: 1868
Rebecca.crossley@jpaget.nhs.uk

Specialist Community Learning Disability Teams:

<table>
<thead>
<tr>
<th>Region</th>
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<tbody>
<tr>
<td>City</td>
<td>01603 638520</td>
</tr>
<tr>
<td>East</td>
<td>01493 841250</td>
</tr>
<tr>
<td>South</td>
<td>01953 450800</td>
</tr>
<tr>
<td>North</td>
<td>01263 835200</td>
</tr>
<tr>
<td>West</td>
<td>01553 666680</td>
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Specialist Community Learning Disabilities Teams: Lowestoft 01502 535020

Adult social services – 03448008014

Julia Hunt Chief Matron ext 2774

Deputy Safeguarding Adults ext 3669

People with a learning disability will be supported to exercise their capacity to make decisions and to consent to treatment where the clinician determines that they have the capacity to do so. In those circumstances where the clinician determines that the person is unable to exercise full capacity to consent to treatment, every effort will be made to ensure that the person understands in simple terms the risks and benefits associated with that treatment.

All Staff are to adopt a person centred approach to care

CARER INVOLVEMENT

The Trust recognises that carers have a unique position in understanding the needs of the person with a learning disability and in helping the staff within the Trust to provide personal care for the patient and to communicate with the patient.

Carers will be encouraged to continue to assist in providing care in partnership with the nursing and medical staff should they wish to do so and will be supported to participate in the nursing assessment and in planning care. Carers Strategy and Carers Contract please see appendix 3

PARTNERSHIP WORKING

Partnership working is vital to ensure a comprehensive person centred approach to the management of hospital care and strategic development of services for the PWLD. This should include:

- The individual with LD
- Their family/carers
- Hospital Staff
- Learning disability liaison nurse
• Residential homes
• Social worker, community LD nurse or key worker
• General Practitioner
• Specialist services, e.g. mental health, epilepsy service
• Advocacy groups
• Charity and voluntary organizations

Partnership working will include:

• GP health assessment and screening Pre admission care planning and preparation
• Development and maintenance of individual health books and health action plans
• Management of long term health conditions
• Health promotion and prevention strategies
• Management of care packages and individual health budgets
• User involvement in service development
• Membership of the LD partnership board health sub group

All care agencies must be prepared to share information and work across the organizations caring for the individual. Key areas of risk are around transfers of care and discharge. **Good practice will involve multi agency case conferencing.**

The Trust will support the development of strong partnership working with colleagues from the local Learning Disability Partnership Trusts. Support from colleagues will be sought in developing strategy, policy and in accessing training and advice. Colleagues will be requested to sit as partners on the Learning Disability Steering Group.

### 2.5 Audit Indicators

**Monitoring and Review**

This policy will be reviewed biannually by the Learning Disability Steering Group to ensure that it continues to support the Trust in developing its strategy to meet the requirements of people with learning disabilities.

The implementation of this policy will be supported by an annual work plan which will be monitored quarterly by the Learning Disability Steering Group.

The Learning Disability Steering Group will submit an annual report to the Clinical Governance Committee summarising the work of the Steering Group and the Trust’s progress in developing services to meet the needs of people with learning disabilities.

Clinical Audit Standards:

To ensure that this guideline is compliant with the above standards, the following monitoring processes will be undertaken:

1. Annual review through the Trust Learning Disability Development Group.
2. Through annual patient satisfaction surveys
3. Twice a year discussion with liaison with advocacy groups and carers forums
2.6 Criteria for staff carrying out the Action

All staff, to attend the Mandatory sessions regarding, Learning Disabilities and Autism.

3.0 GUIDANCE FOR PRACTICE

Responsibilities
Medical Director and Director of Nursing

The medical Director and Director of Nursing have delegated responsibility, to ensure that the Trust provides a health care service to the local population that is accessible, safe and responsive to the needs of patients, including those who may have specific needs arising as a result of a learning disability.

Are responsible for ensuring that policies, processes and monitoring is in place to ensure compliance with this intention and for providing assurance to the Trust Board that the Trust is meeting its obligations to provide a service to people with a learning disability that is consistently safe and of a high quality.

Medical Staff

Medical staff:
Ensure they have completed e-learning programme available at http://www.gmc-uk.org/learningdisabilities/

Are responsible for ensuring that when people with a learning disability access care and treatment at the Trust, the needs of the patient are accommodated in terms of equal and timely access to diagnosis and treatment; adjustment to outpatient services to allow more time for consultation; preparation prior to elective care and individual plans of care that particularly consider aspects such as pain relief and communication.

Have a duty to ensure that where possible, people with a learning disability are helped to understand their condition and are supported within the limits of their capacity to make decisions about their own care and treatment.

Medical Staff should recognise that the carer of a person with a learning disability has considerable insight into the care of that person and that the patient will benefit if care and treatment is delivered in partnership with the carer.

Learning Disability Liaison Nurse (LDLN)

The Acute Liaison Nurse (LDLN) for PWLD’s key role is to lead in the improvement of effective, accessible quality care delivery within acute services which are responsive to the needs of people with learning disabilities.

Therefore the LDLN will be responsible for providing highly specialist leadership that supports the development of acute hospital service good practice.

This will be through close collaborative working with healthcare and multi agency professionals and managing the interface between mainstream hospital services, specialist community services, private and voluntary services and families.
Nursing & Midwifery Staff

Nursing & Midwifery staff:

Are required to ensure that the needs of people with a learning disability and Autism are met through individual assessment and care planning that takes into account the views of the patient and carer and the patient’s personal Health Action Plan.

Have a responsibility to try and ensure that the person with a learning disability is helped to understand the care and treatment provided and staff should allow time to communicate through clear explanation, sign language and use of symbols as appropriate to the ability of the patient.

Staff is expected to support the involvement of the carer in providing personal care so that the person with a learning disability has continuity of care and staffs are better able to recognise and respond to the specific needs of the patient. (Please see appendix 3)

Have a responsibility to act as an advocate for patients with a learning disability who may not be able to clearly express their needs in terms of seeking relief from pain or meeting basic requirements such as eating and drinking.

Rehabilitation Staff

Rehabilitation staff must ensure that where the need for therapy intervention is identified, not only the patient but also the patient’s relatives / carers are involved in the assessment process.

Ensure that any intervention is tailored to the specific needs of the individual.

Rehabilitation staff is required to provide advice and support to the multi-disciplinary team to facilitate a safe and effective discharge.

SPECIFIC OPERATING GUIDELINES

The Disability Discrimination Act (DDA), Equality Act, Autism Act and reasonable adjustments

The DDA, Equality Act and Autism Act requires all health care providers by law to make reasonable adjustments to their services to ensure PWLD have equal access and treatment.

Reasonable adjustments are not just about adapting the physical environment. It should also include considerations around communication, approach and attitude.

Clinical areas are responsible for resourcing and providing the reasonable adjustments to be made in their own areas.

Examples could include:

- Giving individuals an appointment at either the beginning or end of a clinic.
- Giving longer appointment times.
• Placing an individual 1st on the theatre list.
• Allowing a family member to stay all the time.
• Allowing individuals to wear their own clothes to theatre.
• Doing other investigations while individuals are under anaesthetic.
• Giving individuals a place to wait away from the waiting room.
• Offering diversions use of comforters.
• Having one to one nursing.
• Making information much easier to understand.
• Hiring a bed or chair more suited to their individual needs.
• Allowing more time with meals/drinks etc.

Remember anything can be a reasonable adjustment if it supports that individual have safe and equitable access to the care that they require.

**Ethnic minority groups**

The Trust is committed to meeting the needs of all minority groups. Staff must be aware that PWLD who are also from an ethic minority group may have specific difficulties in communicating their cultural needs and wishes e.g. diet, dignity, same sex care.

**Sensory disabilities**

There are a higher percentage of sensory disabilities amongst PWLD. These are sometimes undiagnosed or missed because of a range of complex issues that the individual may have.

**Patient safety**

The Ombudsman’s report (2009) and National Patient Safety Agency (2004) state that “PWLD have a significantly higher risk of adverse events happening to them whilst they are in hospital”.

The Trust has developed a rapid risk assessment to support identification of specific risk areas and need for extra support. Please see appendix 4
This assessment must be completed on admission for every PWLD admitted to the Trust and stored in their health records.

**Difficulty swallowing (Dysphagia) and choking**

Linked physical disabilities can cause increased risk of aspiration pneumonia, (46% PWLD v 15% others National patient safety agency 2004

All staff must asess the individual’s risk in this area. A referral to the speech and language therapist (SALT) to conduct a swallow assessment and provide advice can be made.

The individual must have a dysphagia care plan detailing posture, feeding, suction needs etc.

**Decisions to insert a PEG must be taken after a full best interest decision meeting.**

**Nutrition, Hydration and self care**
Individuals may need extra support to maintain their own nutrition, hydration and hygiene needs whilst in hospital. This should be done through risk assessment followed by comprehensive care planning and supervision as required.

PWLD may not understand “nil by mouth” directives. Health care professionals must take extra steps to ensure that they do not access food or drink in these circumstances and help them to understand the reason for this.

**Epilepsy**

Epilepsy is co morbid in a significant number of PWLD. It accounts for a large number of acute hospital admissions. Epileptic seizures increase the risk of physical injuries, aspiration and deprivation of oxygen.

Most PWLD who have pre-diagnosed epilepsy will have an epilepsy care plan which they should carry with them. There will also be information about their condition in their health books.

Epilepsy monitoring charts must be kept which detail; description of seizure, length, recovery etc.

Key health Professionals involved the PWLD’s care must be kept informed of any changes in medication or management regimes.

Carers and family should be consulted to give insight into behaviours or situations that may precede a seizure.

**Danger to self**

Reasonable adjustments in the form of extra supervision may need to be made for all of the following. It is important that staff consider using the “one to one” policy and risk dependency and support assessment tool.

**Falls**
Staff should follow the Trust Guideline for the Management of Falls in Adult Patients

**Self injurious behaviour**
Some PWLD may display self injurious behaviour. Carers and family who know the patient well must be involved in advising on methods to minimise this.

**Check if the individual has pain, this may be their only way of expressing distress.**

**Lack of insight into dangers**
Individuals with LD may have lack of or low insight into everyday dangers. Care must be taken with sharp objects, medicines, hot water, hot food and drink, open windows etc.

**Mental health**
PWLD can experience the full range of mental illness that affect the whole population. Symptoms are not always recognised because of communication difficulties. Staff must be aware that people with Down’s syndrome have a much higher incidence of early onset dementia than the rest of the population.
Restraint whilst acting in best interests

Some individuals may react with challenging behaviour when about to undergo a procedure or treatment. Consideration must be given as to whether this procedure is absolutely necessary. If the person lacks capacity a best interest meeting must decide that the procedure needs to go ahead. The meeting will discuss and decide on the least restrictive method for achieving the required outcome, (Consent policy and best interest guidance please refer to your Mental Capacity Act 2005 code of practice). A risk assessment will also need to be completed.

Some individuals may need safety sides whilst they are in bed. Some PWLD have poor control of their body posture which may cause them to slide in the bed. This increases the risk of becoming entrapped in safety sides. Hospital staff must follow the safety side matrix (policy on safety sides), conduct a risk assessment and develop an appropriate care plan. The individual may need extra supervision whilst in bed.

Transfers of care

Risk to PWLD is raised significantly during transfers of care. Communication of information between professionals, family and care givers are essential.

Individuals with health books/hospital passports should have these updated before all transfers of care. (See appendix 5)

Diagnostic overshadowing

PWLD can sometime experience diagnostic overshadowing. This may be for several reasons including:

- Difficulty in describing symptoms.
- Attitudes of medical/nursing staff.
- Lack of cooperation with investigation/examination.
- Poor access to screening services.
- High or low pain thresholds.
- Atypical physical presentation.

All health care professionals must be vigilant and observant.

The family or carer who knows the individual best is well placed to describe changes to the person’s health and must be listened to.

Different methods of assessment may need to be considered e.g. pain charts, distress charts.

PWLD must not be excluded from diagnostic tests because of their learning disability.
Pre admission and initial contact with hospital

Preparation for coming into hospital as an emergency or planned admission must be part of an individual’s personal health action plan.

Prior to admission support staff/carers or relatives should support the individual to understand what coming into hospital involves and prepare them accordingly. This may be through contacting the LDLN and use of information DVDs, pre visits, desensitisation programmes, and accessible information. If the community learning disability team is involved in the individuals care, they should also participate in this process.

GP’s should ensure that the hospital is made aware that the patient has a learning disability.

Medical secretaries and administration staff are usually the first point of contact in the acute hospital system. They must be aware that when a patient is identified as having a learning disability this must be entered on the hospital PAS system.

This information must be cascaded to the assessing nurse, medic or health care professional and preparation for reasonable adjustments to be made. This may include contacting the liaison nurse, sending information in an accessible format, adjusting appointment times etc.

Elective Admissions (Please see appendix 6)

Where possible the PWLD will be fully assessed in the pre assessment clinic. The person with a learning disability will receive in addition to the standard documentation, literature describing coming into hospital in an easy read format.

The LDLN will be informed of their impending admission. The nurses contact details will be offered to the PWLD and their carer.

The rapid risk assessment must be initiated in this department and this information cascaded to the admitting ward.

The ward may need to consider making reasonable adjustments e.g. arranging a side room, one to one support etc.

Specific focus will be given to planning discharge arrangements to ensure that adequate help will be available on discharge.

When attending the pre-admission assessment and on admission, the person with a learning disability or their carer / health facilitator will be asked to bring into hospital any copies of care plans and nursing assessments including the personal Health Action Plan.

In pre-admission the assessment nurse will discuss the specific needs of the person and may need to contact the person’s healthcare facilitator, social worker or community nurse to ensure a full assessment of need. **The LDLN will assist with process as necessary.** The assessment will include:
• Swallowing difficulties or dietary needs
• Sensory disabilities such as hearing or visual impairment
• Specific communication needs
• Routine medication, particularly those related to managing epilepsy
• Pain management
• Transport needs
• Special possessions to bring into hospital
• Discharge arrangements

Where possible the person with a learning disability and carer will be offered the opportunity to visit the ward and familiarise themselves with the hospital prior to admission.

The person with a learning disability will be offered the opportunity to ask further questions about the planned procedure.

Where possible the person’s health care facilitator / social worker / community nurse will be contacted and advised of the admission as appropriate.

Outpatient Appointments, Diagnostic Tests and Investigations (please see appendix 6)

In the event of an outpatient appointment the LDLN can work with individuals pre admission to help them understand the process for their investigation. She has access to a number of media resources to assist this.

If the person’s appointment has been booked via ‘Choose and Book’ the details of the person’s disability may not be apparent until the day of appointment and adjustments may be required on the day.

Where possible the person with a learning disability and / or the carer will be asked to bring in with them the person’s Health Action Plan and Hospital Passport.

Details of the person’s health care facilitator / social worker / community nurse should be checked and recorded.

PWLD who require routine clinic visits and/or appointments for diagnostic tests may require reasonable adjustments to accommodate their individual needs for example:

• Time of appointment –
  People with a learning disability may find waiting difficult.

• Length of appointment –
  People with a learning disability will take longer to assimilate information and may take longer to examine.

• Communication needs –
  All diagnostic and pre admission areas must produce information as easy read literature, pictures or models.

• Consent –
  A person with a learning disability may have sufficient capacity to consent to the Procedure but the level of capacity must be determined on the day. If the person is unable to consent, consideration must still be given to helping the person Understand what is going to happen to them.
The Management of Patients with Learning Disabilities and or Autism

The person may well require a carer to accompany them throughout an appointment and into the anaesthetic room and recovery room in Surgery.

- **Environment-**
  People with learning disabilities and or Autism can become frightened by things they do not understand so it may be necessary to remove unnecessary equipment or instrumentation.

- The LDLN can advise on desensitization programmes e.g. needle phobia.

- Individuals should be offered EMLA cream or Ethychloride Spray to numb the area.

- It is worth considering whether blood can be taken whilst an individual is under anaesthetic for another reason.

Where possible the person with a learning disability and or Autism and carer will be offered the opportunity to visit Day Surgery prior to admission.

Tests and investigations can be very frightening to many people with a learning disability so adjustments should be made to reduce anxiety where possible. This should include:

- Preparing the environment to remove unnecessary equipment.

- Ensuring that a carer or family member can remain with the person where possible.

- Providing explanations that are easy to understand and are supported by communication aids such as pictures.

- Not rushing the person.

An assessment should take place when booking a diagnostic test or investigation to ensure that similar considerations are given to those issues addressed in addition staff should also consider:

- **Privacy and Dignity-**
  People with a learning disability may be reluctant to undress and will need help and persuasion to do so.

- **Comforters-**
  People with a learning disability and or Autism may feel the need to hold a comforter throughout a procedure and should be helped to do so as long it does not compromise patient safety.

- **Behaviour-**
  A person with a learning disability and or Autism may react to a frightening situation with challenging behaviour.

- **Directions-**
  People with a learning disability may arrive at an appointment unaccompanied. In these situations additional help may be required to help the person navigate from one department to another.
• Assistance-
  Additional staff assistance may be required to support a person with a learning disability during the test or investigation.

Emergency Admissions (Please see flowchart Page 3)

In the event of an emergency admission:

It must be recognised that in an emergency admission a person with a learning disability may be particularly distressed due to the nature of the admission and may present with challenging behaviour. The person may well be unable to articulate their level of pain and anxiety and be unable to express their symptoms. In this situation staff must contact the person’s carer / health care facilitator / social worker / community nurse as soon as possible along with the LDLN.

In the event that a person with a learning disability and or Autism is brought into the Accident & Emergency Department, the following issues must be considered:

• Pain-
  A person with a learning disability may express the presence of pain through challenging behaviour, head banging or similar signs of distress. Early assessment and treatment of pain is crucial.

• Presence of other disabilities-
  The person may have additional sensory disabilities or suffer from other co-morbidities such as epilepsy.

• Communication-
  Communication will be particularly difficult if the patient is distressed and every effort must be made to explain procedures in a quiet and controlled manner and use supportive communication aids where possible.

• Environment-
  Accident & Emergency is a challenging environment for those without a disability and may present a particularly frightening environment to someone with a learning disability who is unable to understand what is happening to them. Where possible it is advisable to put a person with a learning disability into a cubicle where privacy and a slightly quieter environment can be provided.

Discharge

The JPUHFT guidelines for the management of discharge process for adult patients, aims to ensures that all patients that are ready to be discharged from hospital, do so in a safe, timely and effective manner.

Planning for discharge should commence as soon as a person with a learning disability and or Autism is admitted. People with a learning disability may recover better within their own home environment but must only be discharged when it is safe to do so and when adequate support can be provided for both the patient and carer.

People with a learning disability may require additional support on discharge and the patient’s carer, health care facilitator, community nurse or social worker should be informed so that planned support can be arranged prior to discharge.
A person with a learning disability may live with a partner or family member who also has a learning disability and in these circumstances detailed planning of the discharge and support will be required to ensure a safe discharge.

For comprehensive discharge planning the process must include the individual, their family and/or paid supporters and other professionals who are involved in their care e.g. Community Learning Disability Nurse, Specialist Physiotherapist etc. They can support the gathering of accurate information and identification of potential risks to safe discharge.

Staff must ensure that they check how the individual usually takes their medications and arrange Pharmacy to dispense their tablets in the format they are used to i.e. Blister packs, dosset boxes, boxes with larger print and additional accessible information leaflet etc.

Staff must check with residential care homes if documentation is required to allow care staff to administer any new medication.

Information on diagnosis and treatment plans including follow up appointments should be added to the “Health Book” and new Health Action Plans (HAP)

Careful consideration must be given to providing advice for after-care and treatment. A person with a learning disability may not understand information provided on medication, management of dressings or follow-up appointments. The nurse planning the discharge must ensure that all these issues are addressed so that the discharge is safe and appropriate.

**Flagging and Keeping Data**

The Department of Health and Care Quality Commission require all acute hospitals to put data collection systems in place to monitor the treatment pathways and quality of care that PWLD receive.

A Learning Disability flag will be added to the IPM system for patients known to have a learning disability a data exchange is being negotiated presently between GP’s, PCT and Acute sector we are currently awaiting this data exchange to commence.

If an individual is identified to have a Learning Disability, staff should ask the individual and their carers consent to have the flag added to the system,

Staff without access to PAS should ask the ward clerk or department administrators to do this. Please contact LDLN with necessary details.

PWLD must be supported to understand the Patient Advisory Liaison service (PALS) and complaints system. The LDLN will monitor patient satisfaction via forums and user surveys.

**4.0 Monitoring Compliance**

The MDT audit and Nursing metrics audit tools will be used as a three yearly review of the document. Any shortfalls highlighted will be entered onto an action plan that will be managed by the LD steering group who will monitor the audit action plan.

See Appendix 7 for the Monitoring Table that will be used to conduct monitoring of compliance for this Guideline
Appendix 1

Learning Disabilities Steering Group

Terms of reference

Purpose

The Forum will:-

- Develop systems and processes to address equity of access and equality of care for people with learning disability in the acute hospital.
- Make recommendations to the Equality and Diversity working group for making reasonable adjustments to services for people with learning disabilities.
- Assist staff to develop a person centred approach with adherence to the Human Rights Act, Disability Discrimination Act and Mental Capacity Act.
- Ensure that the views of people with learning disabilities and their carers are integrated into Trust plans and that the patient experience is central to the delivery care and of quality improvements.
- Ensure that processes are put in place and monitored to be compliant with new policy documents, guidance or national drivers that impact upon the care and treatment of people with learning disability in the acute setting.
- Ensure systems are in place for data gathering, monitoring and assessment.

Areas of responsibility

The Steering Group is primarily concerned with the delivery of safe, high quality patient centred care for people with learning disabilities. This will be achieved through ensuring that the appropriate structures, processes and controls are in place.

Structures:

- Work within the comprehensive programme of systems in the Trust that implement safe and appropriate care delivery. Ensure that these meet the needs of people with learning disabilities or that the new systems are developed to do this. E.g. Risk assessment and dependency.
- Support the work of the acute liaison nurse and ensure that the post's primary task is to meet the needs of patients with learning disabilities whilst in the hospital.
- Within the Organisation, have a culture of open and honest reporting and management of any situation that may threaten the quality of the patient experience. Systems will be in place for responding to complaints.
- Divisions are expected to have in place mechanisms that demonstrate that staff are competent to work to appropriate standards of performance.
- Proper and effective use of clinical data and information about patients. Access to patient information is in accordance with all relevant legislation and guidance including Caldicott, The Data Protection Act and Human Rights.
- Work within the mechanisms for Patient and Public Involvement with reasonable adjustments made for people with learning disabilities.
• Have a structure for ensuring that all information is available in accessible format.
• Work with wider learning disability professional community to ensure integration of services and consistency across the region.

Processes:
• Ensure clinical staff is given the knowledge, support and information to care for people with learning disabilities in their area. Through:
  * Training
  * Inline resources
  * Link nurse system
  * Bespoke work
  * LD liaison nurse

• Ensure that all managers, clinical and non-clinical staff are given information to understand the needs of people with learning disabilities and their carers whilst in the acute hospital
• Ensure the needs of BME patients with learning disabilities are assessed and considered.
• Ensure that there are policies and guidelines in place that meet the needs of people with learning disabilities.

Outcomes:
• The Steering Group will assist the Trust to meet the highest standards and expectations of Government directives e.g. CQINN, QUIP. Healthcare for all.
• The Steering Group will ensure that all health aspects of “Valuing People Now” are integrated across the Trust and their effectiveness is continually monitored.
• Data will be gathered on:
  * Admissions
  * Length of stay
  * Patient satisfaction
  * SUIs. Premature death

• There will be evidence of continuous improvement.
• Demonstrate that lessons are learned from adverse incident incidents, complaints, litigation and examples of good practice, and are disseminated within the Trust (and beyond if appropriate)
• The Steering Group chair will coordinate and produce an annual learning disabilities report.

Support and dissemination:
• Ensure the work of the Steering Group is adequately supported and effectively communicated throughout to the Trust Safeguarding Vulnerable Adults Committee.
• Report Trust Steering Group activity to the Regional Valuing people lead and National networks.
Resources:

- Ensure that systems and processes are in place and reviewed to support the needs of people with learning disabilities.
- Ensure adequate human resources are available to support learning disability activity in the Trust.

Membership:

Julia Hunt–Deputy Director of nursing– Chairperson
Rebecca Crossley Acute Liaison Nurse –
One Divisional representative from all Divisions
Invited Link Nurses
Health Care Facilitator (LD service)
Patient Safety representative
Patient Forum representative
Learning Disabilities representative
PALS representative
Allied HCP representative
Parent/Carer representative
Advocacy Group representative
A&E representative
Cromer representative
Modern Matron

Meeting arrangements:

Meetings will be held bi-monthly and
- Arranged 12 months in advance
- Agenda’s and papers to be published 5 working days in advance of the meeting
- Minutes of the proceedings to be taken
- Minutes to be made available on the intranet
- All meeting documentation will be made available in accessible versions

Reports:

To the Trust Safeguarding Vulnerable Adults Committee

Document Control:

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<th>Date</th>
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<td>Dawn Collins</td>
<td>June 2006</td>
<td>Members of the Learning Disabilities Steering Group Safeguarding Adults Committee</td>
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<tr>
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<td>Stevie Read</td>
<td>September 2010</td>
<td></td>
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<td>3.0</td>
<td>Rebecca Crossley</td>
<td>November 2011</td>
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Ratified at:

Date Ratified:

Review Date: September 2011

Effective Date
Appendix 2
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 LDA 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

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

Carer’s Contract

4.5.1

A Carer’s Contract is a written agreement drawn up by the nursing and rehabilitation staff with the full involvement of the carer and where possible, the patient. It helps to define the partnership between the carer and the Trust staff and should provide clarity about what responsibilities the hospital staff and the carer will exercise in caring for the patient and should include:

- When the carer can visit the ward and /or stay.
- The carer’s responsibilities in relation to the other patients on the ward.
- What aspects of personal care will be provided by the carer?
- What aspects of personal care will be provided by hospital staff?
- Whether the carer can be involved in feeding the patient or administering medication
- Whether the carer should be present when the patient is examined, receiving treatment or in consultation with the doctor.
- What information about the patient’s condition should the carer report to staff?
- The extent to which the carer will be involved in decision-making regarding the patient’s care, treatment and discharge.
- Who the carer should speak to if he or she has concerns about the patient or his or her own treatment as a carer.

4.5.2

The carer’s contract will inform the care plan for the patient. At any time the carer may request that he or she changes his or her personal level of involvement with the patient’s care.

4.7

Discharge Planning

4.7.1

Carers should be involved at all stages of planning for the discharge of the patient. This involvement should include:

- Estimating the date of discharge and sharing this with the carer from the outset.
- Discussing and agreeing practical preparations for discharge home.
- Agreeing the date and time of discharge and giving the carer sufficient notice of discharge.
- Ensuring that any equipment or alterations to support safe discharge are in place before discharge takes place.
- The carer has sufficient information to safely care for the patient including information on medication, equipment, patient handling and changes in the patient’s condition that affect the patient’s care needs.
- How to access support and information after discharge.
- Details of follow-up appointments.

4.8

Support and Training for Carers

4.8.1

Carer’s own needs must be recognised and in particular staff should take into account:
- Whether the carer has other commitments, including work.
- The carer’s cultural, racial or religious background that might affect perception of the carer’s role.
- Relationship of the carer to the patient.
- The carer’s ability to manage the role.
- Frailty or disability of the carer.
- Age of the carer, especially if young carer.
- Issues related to access / service provision / housing.

4.8.2

Carers should be offered training in nursing or patient handling techniques prior to discharge if assessed as appropriate.

4.8.3

Carers should be provided with information on the local Carer’s organisation and community services including the Continence Service, Red Cross at Home etc.

4.8.4

Carer’s should be encouraged to have a Carer’s Assessment and be advised on what benefits are available such as Attendance Allowance, Disability Living Allowance or Carer’s Allowance.

4.8.9

Carer’s should be provided with information on the support available from PALS.

4.8.10

The Trust will actively seek the views of carers and local support groups to inform both policy development and the strategic development of services.

5.0

TRANSPORT

5.1

If patients are required to attend follow-up appointments and qualify for transport, carers will only be provided with transport as an escort to the patient if they have particular skills needed by the patient or support is needed on the journey e.g. This might be appropriate if the carer is accompanying a patient with physical or mental incapacity, a child or to act as a translator (DH: 2007)

5.2

Only one escort can travel with a patient under such circumstances and this discretionary provision has to be agreed in advance when transport is booked.

5.3

If transport is provided for a carer, return transport provision is at the discretion of the Ambulance Service and carers must be advised that it cannot be guaranteed.
5.0 IMPLEMENTATION AND MONITORING OF THE STRATEGY

This strategy is to be implemented across the organisation. Monitoring the success of the strategy will be completed using Patient satisfaction surveys and PET. Complaints from relatives/carers will be monitored as per complaints procedure.

6.0 KEY PRIORITIES

This Strategy works in line with the key priorities identified by Department of Health 2010 to ensure the best possible outcomes for carers and those they support, including:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well

Carers Contract

CARER’S CONTRACT

Patient’s ID

Date:

This agreement is to support you in maintaining your role as a carer while the person you care for is a patient in this hospital. This contract recognises that as a carer you are an expert in providing day to day care to the person and that you can help staff in looking after the patient and meeting his / her needs.

The following contract is a written agreement drawn up between the nursing and rehabilitation staff and you as the patient’s carer. Where the patient is able to exercise choice it also includes the agreement and wishes of the patient. It describes how we can work in partnership for the benefit of the patient and specifies which responsibilities we as hospital staff undertake to provide and those aspects of care that you will be continuing to provide.

Arrangements for visiting or staying on the ward.

How you can continue to act as a carer without affecting the other patients on the ward.
What aspects of personal care will be provided by the carer?

What aspects of personal care will be provided by hospital staff?

How you can be involved in feeding the patient or administering medication.

Whether you can be present when the patient is examined receives treatment or has a consultation with the doctor.
What information about the patient’s condition it would be helpful for you to share with staff.

How you will be involved in decision-making regarding the patient’s care, treatment and discharge.

Who you should speak to if you have concerns about the patient or your own treatment as a carer.

Name of Carer (PRINTED)………………………………………………………………………………………

Signature of Carer ………………………………………………………………………………………………

Signature on behalf of the Trust …………………………………………………………………………………

Signature of Patient (where appropriate)……………………………………………………………………
### Appendix 4

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

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<tr>
<td><strong>Personal safety</strong></td>
<td></td>
</tr>
<tr>
<td>• No issues identified</td>
<td>0</td>
</tr>
<tr>
<td>• Requires regular observation and reinforcement to maintain safety</td>
<td>1</td>
</tr>
<tr>
<td>• Level of learning or physical disability requires half hourly checks to maintain safety</td>
<td>2</td>
</tr>
<tr>
<td>• Mental health status affects ability to maintain safety</td>
<td></td>
</tr>
<tr>
<td>• Additional sensory disability, blind or deaf</td>
<td></td>
</tr>
<tr>
<td>• Unable to maintain own safety due to level of learning disability/autism, may wander, remove medical devices e.g. cannulas, drains</td>
<td>3</td>
</tr>
<tr>
<td>• Complex physical disabilities require continuous observation and management of posture to maintain airway.</td>
<td></td>
</tr>
<tr>
<td>• High risk of pressure area breakdown (Waterlow)</td>
<td></td>
</tr>
<tr>
<td>• High risk of falls (falls assessment)</td>
<td></td>
</tr>
<tr>
<td>• Safeguarding issue identified</td>
<td></td>
</tr>
<tr>
<td><strong>Swallowing, Nutrition, hydration</strong></td>
<td></td>
</tr>
<tr>
<td>• No previous or current history of swallowing issues</td>
<td>0</td>
</tr>
<tr>
<td>• Previous history of swallowing issues but has not been formally assessed</td>
<td>1</td>
</tr>
<tr>
<td>• Requires support to ensure adequate food and fluid intake</td>
<td></td>
</tr>
<tr>
<td>• Requires safe positioning or additional support for eating/drinking/non oral feeding</td>
<td>2</td>
</tr>
<tr>
<td>• Long term feeding via a peg or NGT and is NBM</td>
<td></td>
</tr>
<tr>
<td>• History of recurrent chest infections or unintentional weight loss</td>
<td></td>
</tr>
<tr>
<td>• Assessment indicates high risk of Dysphagia</td>
<td>3</td>
</tr>
<tr>
<td>• On modified food/thickened fluids</td>
<td></td>
</tr>
<tr>
<td>• Requires one to one support whilst eating/drinking for safe swallowing</td>
<td></td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td></td>
</tr>
<tr>
<td>• Good verbal communication and understanding</td>
<td>0</td>
</tr>
<tr>
<td>• Indicates when/where has pain</td>
<td></td>
</tr>
<tr>
<td>• Some verbal communication uses non verbal systems to supplement.</td>
<td>1</td>
</tr>
<tr>
<td>• Requires additional time to process information and respond</td>
<td></td>
</tr>
<tr>
<td>• Uses some non verbal signs, facial expressions, body language or behaviour to communicate.</td>
<td>2</td>
</tr>
<tr>
<td>• Extremely limited communication</td>
<td></td>
</tr>
<tr>
<td>• Requires support from carers to interpret need.</td>
<td>3</td>
</tr>
<tr>
<td><strong>Mental capacity</strong></td>
<td></td>
</tr>
<tr>
<td>• Assessment indicates no capacity issues</td>
<td>0</td>
</tr>
<tr>
<td>• Can make own decisions and/or consent to treatment with clear explanation</td>
<td></td>
</tr>
<tr>
<td>• Understands simplified explanation of procedures</td>
<td></td>
</tr>
<tr>
<td>• Requires reinforcement, extra time, accessible information to support decision making</td>
<td>1</td>
</tr>
<tr>
<td>• Has difficulties understanding complex treatments/interventions but will consent with reinforcement and support.</td>
<td></td>
</tr>
<tr>
<td>• Is unable to understand, retain, weigh up, communicate back and make decisions related to treatment/interventions (lacks capacity).</td>
<td>2</td>
</tr>
<tr>
<td>• Very unlikely to comply with treatment/interventions</td>
<td>3</td>
</tr>
<tr>
<td><strong>Epilepsy</strong></td>
<td></td>
</tr>
<tr>
<td>• No known seizure activity</td>
<td>0</td>
</tr>
<tr>
<td>• Seizures well controlled by medication or infrequent</td>
<td>1</td>
</tr>
<tr>
<td>• Poorly controlled or unpredictable seizures</td>
<td></td>
</tr>
<tr>
<td>• Seizure activity increased by illness or anxiety</td>
<td>2</td>
</tr>
<tr>
<td>• Seizure activity is prolonged or difficult to recognise leading to loss of consciousness.</td>
<td></td>
</tr>
<tr>
<td>• High risk of airway obstruction or aspiration during seizures (history)</td>
<td>3</td>
</tr>
<tr>
<td><strong>Behaviours and Anxieties</strong></td>
<td></td>
</tr>
<tr>
<td>• No issues identified</td>
<td>0</td>
</tr>
<tr>
<td>• May become anxious in new environments, needs reassurance and extra time to reduce anxiety</td>
<td>1</td>
</tr>
<tr>
<td>• May display inappropriate behaviour, needs clear boundaries and reinforcement</td>
<td></td>
</tr>
<tr>
<td>• Regularly displays inappropriate behaviours e.g. stripping.</td>
<td></td>
</tr>
<tr>
<td>• Sometimes displays aggressive behaviours</td>
<td>2</td>
</tr>
<tr>
<td>• Severe hospital phobia or unable to wait</td>
<td></td>
</tr>
<tr>
<td>• Regularly displays aggressive behaviours to self or others, high risk of injury.</td>
<td></td>
</tr>
<tr>
<td>• Requires own carers to manage needs.</td>
<td>3</td>
</tr>
</tbody>
</table>

All documents relating to Learning Disabilities and/or Autism are on the Trust intranet:
Follow the link from Practice Development and Education Department – Vulnerable adults - Learning disabilities

---

Page 2 overleaf must be completed Total:
### Rapid Risk Assessment for patients with Learning Disabilities and/or Autism

<table>
<thead>
<tr>
<th>Score = 0-8 low risk:</th>
<th>Score = 9-12 Medium risk:</th>
<th>Score = 13-18 High risk:</th>
</tr>
</thead>
</table>

#### Care Bundles

**Low risk**
- Complete all Trust risk assessments i.e. Falls, Waterlow, MUST, epilepsy charts.
- Implement basic nursing care monitoring charts e.g. fluid charts, food charts, epilepsy charts.
- Liaise with link practitioner for further advice.
- Liaise with carers to identify usual support and communication needs.
- Check if known to specialist learning disability team (see below).
- Ensure LD or autism code added to PAS (with consent).

<table>
<thead>
<tr>
<th>Medium risk</th>
<th>As above plus:</th>
<th>Tick on completion</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Increase level of supervision and observation</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confirm level of support that can be offered by carers, document on care plan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consider increased support needs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Use alternative methods to assess potential clinical issue e.g. distress tool (on LD site)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Make referrals to appropriate health care professionals e.g. SALT, Physiotherapist, Dietitian etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Involve specialist learning disability team (see below)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**High risk**
- Complete full risk dependency and support assessment tool (on LD site).
- Make referral to Acute Liaison Nurse ext 3732 Bleep 1868.
- Agree additional support needs with senior nurse.
- Ensure principles of the Mental Capacity Act are followed in relation to best interest and consent.
- Arrange MDT meeting to support safe discharge planning and continuing care needs.

**DOCUMENT ALL ACTIONS CLEARLY IN THE PATIENT’S HEALTH CARE RECORDS**

Acute Liaison Nurse for people with learning disabilities: Rebecca Crossley: 01493 453732 Bleep: 1868
Rebecca.crossley@jpaget.nhs.uk

Specialist Community Learning Disability Teams:

- City 01603 638520
- East 01493 841250
- South 01953 450800
- North 01263 835200
- West 01553 666680

Specialist Community Learning Disabilities Teams: Lowestoft 01502 535020
Adult social services - 03448008014

Assessment completed by:

<table>
<thead>
<tr>
<th>Print name:</th>
<th>Signature:</th>
<th>Date (dd/mm/yy):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 5

Hospital Passport
For vulnerable people coming to James Paget University Hospitals Foundation Trust

My name is:

If I attend an appointment or go into hospital this passport needs to go with me and stay with me at all times.

Please look at it
It tells you

• Things you MUST know about me
• Things that are important to me
• My likes and dislikes

This information belongs to me. Please return it to me when I go home.
Appendix 6

Things you must know about me

Name: 
Likes to be known as: 
Date of Birth: 
Address: 
Tel No: 

How to communicate with me:

Contact person: 
Relationship e.g. family member, Support Worker:
Address: 
Tel No: 

My support needs and who gives me the most support:

Date completed by
### Things you must know about me

<table>
<thead>
<tr>
<th>Allergies:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Heart/Breathing problems:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Risk of choking, Dysphagia (eating, drinking &amp; swallowing):</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>GP:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Address:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Tel No:</th>
</tr>
</thead>
</table>

**Other services/professionals involved with me:**

<table>
<thead>
<tr>
<th>Spiritual needs:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Religion:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Religious Needs:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Ethnicity:</th>
</tr>
</thead>
</table>

**What makes me anxious, upset or worries me (e.g. the dark, noise, crowds etc) and how do I show this?**

**What helps me when I feel like this?**

**Date completed**

**by**
### Things you must know about me

**Current medication:**

<table>
<thead>
<tr>
<th>Date completed</th>
<th>by</th>
</tr>
</thead>
</table>
Things that are important to me

How you know I am in pain: (posture, skin colour, sounds)

Moving around: (Posture in bed, walking aids, transfers, hoisting)

Personal care: (Dressing, washing, etc)

Seeing/Hearing: (Problems with sight or hearing)

How I eat: (Food cut up, help with eating, consistency of food)

Date completed by
Things that are important to me

How I drink: (drink small amounts, thickened fluids)

How I keep safe: (Side room, Low bed, Bed rails, and support from familiar staff)

How I use the toilet: (Continence aids help to get to the toilet)

Sleeping: (Sleep pattern/routine)

Date completed by
### My likes and dislikes

**Likes:** for example - what makes me happy, things I like to do, things that are important to me
i.e. watching TV, reading, music, routines.

**Dislikes:** for example food I don’t like, physical touch, needles

<table>
<thead>
<tr>
<th>Things I like</th>
<th>Things I don’t like</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Please do this:</strong></td>
<td><strong>Don’t do this:</strong></td>
</tr>
</tbody>
</table>

Date completed by

---

Title: Management of Patients with Learning Disability & Autism  
Author: Rebecca Crossley LDLN  
Review Date: May 2015  
Ref: GUI/TWD/RC/3105/01  
Issue Date: May 2012  
Page 42 of 53
Hospital Passport is based on original work by Gloucester Partnership NHS Trust and the South West London Hospital Access to Acute Group and Alzheimer's organisation.

Additional copies of Hospital Passport can be downloaded from James Paget Internet Learning Disabilities Internet Page.
LD sub group/ V3 May 2012 review May 2013
Emergency admissions
Reasonable Adjustments

• If it is clinically safe to do so would the patient be less anxious to be treated in a quieter area?

• If the patient is becoming anxious and carer’s report that they generally cannot cope with waiting, consider:  
  - offering a quiet room for patient and carer to wait in
  - could the patient be seen sooner, i.e. ‘fast track’ patient

• If the carer is unable to contribute to an assessment, contact should be made with other agencies involved e.g. The Community Nursing Learning Disability Team.

• Where assessment identifies need for additional resources, the nurse should make immediate contact with the appropriate lead nurse to discuss what is required and document in the care plan. Ensure patient is safe during this process and not left on their own.
## Treatment in A&E, EADU Gold Standard Protocol

<table>
<thead>
<tr>
<th>Gold Standard</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Who</strong></td>
</tr>
<tr>
<td>Appropriate clinical staff</td>
</tr>
<tr>
<td><strong>What</strong></td>
</tr>
<tr>
<td>Treatment of medical conditions with increased interventions, some of which are likely to be invasive.</td>
</tr>
<tr>
<td><strong>When</strong></td>
</tr>
<tr>
<td>Standard to be agreed for period of assessment</td>
</tr>
</tbody>
</table>

### 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 LDLN?
- 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 ‘BLEEP’ 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).
- If patient is to be admitted ensure all reasonable adjustment required are followed onto ward environment.
OUT-PATIENTS

Reasonable adjustments

Be prepared to have be flexible in your approach to meet individual needs

Can easy read letter \ appointment information be sent out?

Can you offer a first appointment when the Clinic is not so busy?

Can a double appointment be offered to give the patient more time to discuss and understand their current health condition?

Is there a quiet area where the patient can sit if he/she becomes distressed?

Read the patient's Communication Passport 'My Health Record'.

Can you talk through an easy read \ photo leaflet explaining the treatment?

If consent is required take extra time to explain - if there is doubt the patient does not understand, involve carer \ family and MDT with 'best interests'decision.

ALWAYS CONSIDER:
How can you make the appointment more accessible to the patient?
Quick top tips on Planned Admission

Would it help the patient to visit the ward and meet people who will be involved in their care before their admission?

If the carer chose to assist in the care delivery, welfare of the carer must be considered, for example refreshments should be offered, accommodation should be discussed and how they could be given a break in line with the trust carer’s policy. Complete carers contract available on the intranet.

In discussing carer’s involvement it is not obligatory on their part however paid carer’s will work in partnership with acute hospital staff to ensure the patient receives the best care possible.

It is best practice to hold case conference and discharge meetings where the care of the patient is complex.

Consider involving carer’s as part of the handover process where possible.

Make all attempts to involve carer’s with any decisions around best interests.

Where possible maintain the patients established routine keeping changes to a minimum.

Ensure all information about patient is shared with all ward staff and followed. This will often be provided by carer’s and should be kept at the bedside where it is visible.

PLANNED ADMISSION- Reasonable Adjustment

1. The Ward manager should be informed in advance by medical, secretarial or Outpatient staff that a patient with a learning disability is to be admitted with date, time and procedure.

2. In circumstances where a nurse, support worker, or social worker is involved in the Out-Patient consultations and they are aware of a planned admission they should make contact with the ward manager of the admitting ward to discuss admission arrangements, and pre ward visit.

3. Contact with the patient, main carer or professional responsible for care to the admission date to discuss:
   - the admission arrangements
   - treatment and procedure plans
   - the individual’s current care needs
   - Issue of Consent and patients ability to consent.

4. Any special resources which may be required to be in place for admission (if a prolonged admission is anticipated it may be possible to liaise with the carer’s regarding the
5. The involvement of any Allied Health Professionals (AHPs) e.g. physiotherapist, occupational therapist, speech therapist or social worker in order that liaison can be established with relevant Trust staff.

Upon admission to hospital any care needs that the client has are the responsibility of hospital staff.
### Appendix 7 - Equality Impact Assessment

**Policy or function being assessed:** The Management of Patients with Learning Disabilities and or Autism  
**Department/Service:** Education and Practice Development  
**Assessment completed by:** Rebecca Crossley  
**Date of assessment:** May 2012

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Describe the aim, objective and purpose of this policy or function.</td>
<td>This policy sets out the standards of service that the Trust is committed to delivering to address the inequalities faced by people with Learning Disabilities and Autism.</td>
</tr>
</tbody>
</table>
| 2i. | Who is intended to benefit from the policy or function? | **Staff □X**  
**Patients □ X**  
**Public □ X**  
**Organisation □ X** |
| 2ii | How are they likely to benefit? | To ensure that acute services provided to PWLD are equitable and safe.  
To provide a responsive service to meet PWLD’s individual needs and that of their carers also to make reasonable adjustments for their disability.  
To offer staff guidance and support to hospital staff when caring for PWLD  
To set out the standards to demonstrate the Trusts commitment to address the health inequalities that this patient group face. |
| 2iii | What outcomes are wanted from this policy or function? | Ensure comparative health outcomes for people with learning disabilities and Autism. |

**For Questions 3-11 below, please specify whether the policy/function does or could have an impact in relation to each of the nine equality strand headings:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Impact</th>
</tr>
</thead>
</table>
| 3. | Are there concerns that the policy/function does or could have a detrimental impact on people | Y  
N x |
<p>| If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data |</p>
<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Y</th>
<th>N</th>
<th>X</th>
<th>Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>gender</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>5</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>disability</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>6</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>sexual orientation</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>7</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>pregnancy or maternity</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>8</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>religion/belief</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>9</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>transgender</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>10</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>age</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>11</td>
<td>Are there concerns that the policy/function does or could have a detrimental impact on people due to their <strong>marriage or civil partnership</strong>?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>If yes, what evidence do you have of this? E.g. Complaints/Feedback/Research/Data</td>
</tr>
<tr>
<td>12</td>
<td>Could the impact identified in Q.3-11 above, amount to there being the potential for a disadvantage and/or detrimental impact in this policy/function?</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>Where the detrimental impact is unlawful, the policy/function or the element of it that is unlawful must be changed or abandoned. If a detrimental impact is unavoidable, then it must be justified, as outlined in the question above.</td>
</tr>
<tr>
<td>13</td>
<td>Can this detrimental impact on one or more of the above groups be justified on the grounds of</td>
<td>Y</td>
<td>N</td>
<td>X</td>
<td>Where the detrimental impact is unlawful, the policy/function or the element of it that is unlawful must be changed or abandoned. If a</td>
</tr>
</tbody>
</table>
promoting equality of opportunity for another group? Or for any other reason? E.g. providing specific training to a particular group. | detrimental impact is unavoidable, then it must be justified, as outlined in the question above.

<table>
<thead>
<tr>
<th>14. Specific Issues Identified</th>
<th>Please list the specific issues that have been identified as being discriminatory/promoting detrimental treatment</th>
<th>Page/paragraph/section of policy/function that the issue relates to</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td>1.</td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

15. Proposals

How could the identified detrimental impact be minimised or eradicated?

If such changes were made, would this have repercussions/negative effects on other groups as detailed in Q. 3-11?

Y N

16. Given this Equality Impact Assessment, does the policy/function need to be reconsidered/redrafted?

Y N

17. Policy/Function Implementation

Upon consideration of the information gathered within the equality impact assessment, the Director/Head of Service agrees that the policy/function should be adopted by the Trust.

Please print:

**Name of Director/Head of Service:** Tina Cookson  **Title:** Director of Nursing  **Date:** May 2012
### Name of Policy/function: Learning Disability Liaison Nurse

**Author:** Rebecca Crossley  
**Date:** May 2012

(A paper copy of the EIA which has been signed is available on request).

<table>
<thead>
<tr>
<th>18. Proposed Date for Policy/Function Review</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 2015</td>
</tr>
</tbody>
</table>

Please detail the date for policy/function review (3 yearly):

<table>
<thead>
<tr>
<th>19. Explain how you plan to publish the result of the assessment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Completed E.I.A’s must be published on the Equality pages of the Trust’s website).</td>
</tr>
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| Standard Trust process |

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<th>20. The Trust Values</th>
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In addition to the Equality and Diversity considerations detailed above, I can confirm that the four core Trust Values are embedded in all policies and procedures.

They are that all staff intend to do their best by:

**Putting patients first, and they will:**
- Provide the best possible care in a safe clean and friendly environment,
- Treat everybody with courtesy and respect,
- Act appropriately with everyone.

**Aiming to get it right, and they will:**
- Commit to their own personal development,
- Understand theirs and others roles and responsibilities,
- Contribute to the development of services

**Recognising that everyone counts, and they will:**
- Value the contribution and skills of others,
- Treat everyone fairly,
Support the development of colleagues.

Doing everything openly and honestly, and they will:
   Be clear about what they are trying to achieve,
   Share information appropriately and effectively,
   Admit to and learn from mistakes.

I confirm that this policy/function does not conflict with these values. ☑