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<b>Author / Title:</b> UHMB contact: Brian Evans, Clinical Nurse Specialist for Learning Disabilities	<b>Responsibility:</b> Corporate Services	
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<b>CONTENTS</b>		
		<b>Page</b>
	BEHAVIOURAL STANDARDS FRAMEWORK	4
1	SUMMARY	5
2	PURPOSE	5
3	SCOPE	5
4	STANDARD OPERATING PROCEDURE	6
4.1	Definitions	6
4.1.1	Definition of Learning Disability	6
4.1.2	Definition of Autism	6
4.2	Communication	6
4.3	Hospital Passport	8
4.4	Specialist Community Learning Disability Teams	8
4.5	South Cumbria Adult Autism Diagnostic Service	8
4.6	Learning Disability Support Staff	8
4.7	Consent and Best Interest Decision Making	8
4.7.1	Children and young people under 16 years old	8
4.7.1.1	Basic principles	8
4.7.1.2	What happens if a child withholds consent?	9
4.7.1.3	What happens if parents withhold consent?	9
4.7.2	Adults	10
4.7.2.1	Mental Capacity Act 2005 (Applies from age 16 onwards)	10
4.7.2.2	Care and Treatment	11
4.7.2.3	Advanced decisions, lasting power of attorney and/or court of protection	12
4.7.2.4	Determining Best Interests	12
4.7.2.5	Resolution of Disputes	12
4.8	Compliments, Comments, Concerns and Complaints	13
4.9	Preparation for Hospital Visits, Admissions and Discharges	13
4.10	Sharing Information	14
4.11	Additional Support	14
4.12	Funding issues if additional support in hospital is required	14
4.13	Responsibilities	15
4.13.1	General Staff Responsibilities	15
4.13.2	Line Manager Responsibilities	15
4.14	Acknowledgements	15
5	ATTACHMENTS	16
6	OTHER RELEVANT / ASSOCIATED DOCUMENTS	16
7	SUPPORTING REFERENCES / EVIDENCE BASED DOCUMENTS	16
8	DEFINITIONS / GLOSSARY OF TERMS	17
9	CONSULTATION WITH STAFF AND PATIENTS	17
10	DISTRIBUTION PLAN	17
11	TRAINING	18
12	AMENDMENT HISTORY	18
Appendix 1	Learning Disability Hospital Admission Pathway	19
Appendix 2	Funding of support if required by adults with learning disabilities on admission to hospital	20
Appendix 3	Useful Contacts	22

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

## BEHAVIOURAL STANDARDS FRAMEWORK

To help create a great place to work and a great place to be cared for, it is essential that our Trust policies, procedures and processes support our values and behaviours. This document, when used effectively, can help promote a workplace culture that values the contribution of everyone, shows support for staff as well as patients, recognises and celebrates the diversity of our staff, shows respect for everyone and ensures all our actions contribute to safe care and a safe working environment - all of which are principles of our Behavioural Standards Framework.

### Behavioural Standards Framework – Expectations ‘at a glance’

Introduce yourself with #hello my name is... 	Value the contribution of everyone	Share learning with others
Be friendly and welcoming	Team working across all areas	Recognise diversity and celebrate this
Respect shown to everyone	Seek out and act on feedback	Ensure all our actions contribute to safe care and a safe working environment
Put patients at the centre of all we do	Be open and honest	For those who supervise / manage teams: ensure consistency and fairness in your approach
Show support to both staff and patients	Communicate effectively: listen to others and seek clarity when needed	Be proud of the role you do and how this contributes to patient care

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

## 1. SUMMARY

This guideline supports people with learning disabilities, autism and complex needs to access acute hospital health care for diagnostic investigations or treatment, or for emergency admission.

The guideline is to ensure there is:

- Equality of access to services (as outlined in Equality Act 2010<sup>1</sup>)
- Engagement of individuals in all aspects of decision making about their health care
- Availability of accessible information as identified in the Accessible Information Standards (2016)<sup>2</sup> for individuals and those involved in their health care
- Definition of the role of hospital and community multi-disciplinary teams

### Rationale

There is evidence that people with learning disabilities, autism and complex needs have poorer health outcomes than the general population. All health care services are committed to ensuring individuals have access to quality health care which meets their specific needs and practising accordance with legal requirements outlined specifically in the Mental Capacity Act 2005<sup>3</sup> and the Equality Act 2010<sup>1</sup>.

## 2. PURPOSE

The objective of this guideline is to ensure individuals are able to access high quality personalised health care when attending University Hospitals of Morecambe Bay services for diagnostic investigations or treatment.

- To enable staff to develop a better understanding of the specific needs of individuals to enable them to provide person centred care and treatment.
- To clarify the role, responsibilities and limitations of all people involved in the individuals care and treatment including family, carers, community teams and hospital professionals
- To provide general information which may be useful when supporting individuals to plan and access hospital services
- To promote the use of the Hospital Passport and other resources for individuals who access hospital services.
- To promote multi-disciplinary collaborative working

## 3. SCOPE

This guideline provides a care pathway for people with learning disabilities, autism and complex needs who require hospital and community care services. It is intended for use by all staff employed within University Hospitals of Morecambe Bay NHS Foundation Trust, who must work in partnership with other local service providers in relation to the services they provide to individuals.

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

## 4. GUIDELINE

### 4.1 Definitions

#### 4.1.1 Definition of Learning Disability

The Department of Health defined a Learning Disability as:

‘A significantly reduced ability to understand new or complex information or learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development’

(Valuing People Now, DoH, 2009)<sup>4</sup>

Learning disability does not include:

- The development of intellectual, social or adaptive impairments after the age of 18 this is classified as an acquired brain injury (ABI).
- Complex medical conditions that affect intellectual and social / adaptive functioning e.g. dementias, Huntington’s disease, where there was no prior diagnosis of a global learning disability
- Specific learning difficulties: e.g. dyslexia, literacy or numeracy problems, or delayed speech and language development, where there was no prior diagnosis of a global learning disability

People with learning disabilities may have additional complex needs such as challenging behaviour, dementia, physical disability, mental health issues and specific syndromes including Down syndrome, Rhetts’s syndrome and Prader-Willi syndrome etc.

#### 4.1.2 Definition of Autism

Individuals with a formal diagnosis of Autism or Asperger’s have impairments in social interaction and developmental language and communication skills combined with rigid, repetitive behaviours and sensory differences.

People with learning disabilities, autism and complex needs may have difficulty with:

- Communicating and expressing needs and choices.
- Understanding and retaining their diagnosis, treatment options or services available to them.
- Understanding the consequences their decisions can have on their health status.
- Adapting to a hospital environment and the expectations of hospital staff.

### 4.2 Communication

Effective communication can overcome barriers to healthcare. All staff need to communicate effectively as a multi-disciplinary team with individuals, their families and carers.

All staff must consider the individuals learning style and communication needs by asking them or someone who knows them well their preferred communication method. All information should be in a format that is understandable and accessible for each individual

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

for example verbal, pictorial or objects of reference.

Please refer to Accessible Information Standard (2016)<sup>2</sup>

<https://www.england.nhs.uk/ourwork/accessibleinfo/>

All hospital staff have a responsibility to ensure information is accessible for each individual. There are links to resources (see page 21) within this document however for further support and advice please contact the trust's clinical nurse specialist for learning disabilities and/or the community learning disability team.

Please find below communication tips:

- Check if the person has a hospital passport or communication passport
- Check the persons' hearing status if possible, e.g. do they have a hearing aid?
- Speak slowly and clearly and avoid complex language.
- Check understanding e.g. by asking people to explain what they have understood.
- Use short sentences and easy words.
- Supplement verbal information by the use of written instructions, symbols, pictures objects, or by modelling/ demonstrating what will happen
- Use gestures, body language and facial expression to supplement words but be aware that these may have different meanings across cultures.
- Use environmental and contextual cues where appropriate.
- Avoid the use of technical words, jargon and abbreviations.
- Avoid the use of words, which can have a literal meaning e.g. Wait a minute, take a seat.
- Avoid the use of complex instructions and spatial directions e.g. turn right at the end of the corridor and take the third door on the left.
- Be prepared for pauses and silences. People with learning disabilities may have difficulty processing information and formulating a response and may need more time to think about what has been said.
- Reduce distractions as far as possible.
- Make sure the patient remains involved in the discussions as fully as possible; However, should additional information be required this can be sought from family members or carers as appropriate. Seek permission from the service user to do this and continue to include them in the dialogue.

Adapted from: Tips for Effective Spoken Communication with People with a Learning Disability. [Promoting Access to Healthcare for People with a Learning Disability - A Guide for Frontline NHS Staff: NHS Quality Improvement Scotland 2006.]<sup>5</sup>

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

### 4.3 Hospital Passport

The Hospital Passport is a document which provides important information about an individual's health and support needs. This document belongs to the individual. If the individual arrives at the hospital without a hospital passport there may be an electronic copy uploaded onto Lorenzo in *Clinical Notes Section*.

If the person does not have a hospital passport the individual should be supported to complete one, a blank template is available on the learning disability page of the Trust's internet page. This is accessible to the public. Please see link below.

<https://www.uhmb.nhs.uk/patients-and-visitors/coming-into-hospital/hospital-passport>

### 4.4 Specialist Community Learning Disability Teams

There are children and adult community learning disability services based in South Cumbria and North Lancashire. Anyone can contact the learning disability teams for advice and support. See contact details at the end of this guideline.

The teams support people to access health care services by working collaboratively. They can help to ensure that all services are accessible and meet the needs of individuals who have a learning disability and complex needs.

### 4.5 South Cumbria Adult Autism Diagnostic Service

The Autism Service has a base in South Cumbria and is county wide. Upon referral the team can provide adults with an assessment for Autism and a limited number of follow up appointments to help individuals understand and manage their new diagnosis of Autism.

### 4.6 Learning Disability Support Staff

Staff working for independent sector provider services/local authority/health providers who are employed to support individuals with learning disabilities to live in their own homes or provide other community based support.

### 4.7 Consent and Best Interest Decision Making

#### 4.7.1 Children and young people under 16 years old

Refer to "Consent what you have a right to expect": A guide for children and young people" (DH 2001)<sup>6</sup>

##### 4.7.1.1 Basic principles

When caring for children there is an overriding duty to act in the best interests of the child. When making decisions regarding treatment, the child or young person should be involved in the decision as much as possible, depending on their level of understanding. If the child is not capable of consenting themselves, the consent of a person with parental responsibility is required, or in some cases, the court, in order to proceed with treatment.

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

Children under 16 can consent to treatment if they are competent to understand what is being proposed. It is up to the practitioner to decide whether the child has the maturity and intelligence to understand fully the nature of the treatment, the options, the risks and the benefits involved. A child who has such understanding is considered Gillick competent<sup>7</sup>. The parents cannot overrule the child's consent when a child is judged to be Gillick Competent. For example, a 15-year-old Gillick competent young person can consent to receiving tetanus immunization even if their parents do not agree with it.

Children under 16 who are not Gillick competent, and very young children, cannot either give or withhold consent. Those with parental responsibility need to make the decision on their behalf.

In an emergency, when a person with parental responsibility is not available to consent, the practitioner has to consider what the child's best interests are and then act appropriately. The treatment should be limited to what is reasonably required to deal with the particular emergency. Wherever possible, it is advisable to discuss the case with a senior colleague, if available. In all cases, it is important to document in full what decisions were made and why.

#### 4.7.1.2 What happens if a child withholds consent?<sup>7</sup>

If the child is not Gillick competent, the parents can consent on behalf of the child, even if the child is refusing the treatment. Careful consideration should be given to whether lack of consent by a distressed child should be overridden. Often if sufficient time is given, the parents may be able to persuade the child that the intervention will be beneficial. Staff should aim to work in partnership with the parents, assuming that the child's best interests are paramount.

A competent child is legally entitled to withhold consent to treatment. However, even though the child or young person may be considered to be Gillick competent, there are some situations where their refusal can be overridden by the Courts. The refusal of a Gillick competent child can only be overridden by the Court's inherent jurisdiction. If the treating doctor believes that the withholding of consent may be detrimental to the patient's wellbeing, legal advice may be required. It may be necessary for a court to determine whether treatment can be given against the wishes of a competent young person.

Patients age 16-17 can withhold consent to treatment, but this can be overruled only in exceptional circumstances i.e.

- If a young person aged 16-17 *lacks* capacity to consent to treatment, treatment can be given in their best interests as determined by the Decision Maker following normal Mental Capacity Act 2005<sup>3</sup> procedures.
- If the young person *has* capacity to withhold consent only the court can overrule their decision

#### 4.7.1.3 What happens if parents withhold consent?

If a competent child refuses treatment and his/her parents agree with their decision, but staff do not believe that it is in the best interests of the child, staff should take legal advice on how to proceed. The same principle applies if the parents of a non-competent child choose to withhold consent for what staff consider to be necessary treatment. Staff are

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

obliged to act in the child's best interests and may need to apply for a court order to proceed with treatment.

## 4.7.2 Adults

### 4.7.2.1 Mental Capacity Act 2005<sup>3</sup> (Applies from age 16 onwards)

The Mental Capacity Act (MCA) 2005<sup>3</sup> provides a statutory framework to empower and protect people who may lack the capacity to make some decisions for themselves, e.g. people with learning disabilities, dementia, mental health problems, stroke and head injury.

Healthcare professionals must assume that the person has capacity to make decisions. Health professionals must make every effort to help and support the person to maximise their potential to make their own decisions or, at least, to participate as fully as possible in the decision making process. Staff must consider how to convey information to the person and how to make the most of the abilities the person has. This may include choosing the best time and location for the assessment, allowing the person sufficient time to become familiar with the issues and communicating in easy to understand language or using pictures and photos.

The MCA applies to all people who work in health and social care involved in the treatment, care or support of people over the age of 16 who are unable to make all or some decisions for themselves.

The MCA is accompanied by a statutory Code of Practice, which provides guidance on how it will work on a day-to-day basis. Anyone working in a professional or paid role with people who lack capacity will have a legal duty to refer to the Code of Practice<sup>8</sup>. It can be found at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

#### The Act is underpinned by five key principles:

- **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. (In England this refers to people over the age of 16 in relation to consent to treatment)
- **Individuals being supported to make their own decisions** - People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision. This means that staff should make every effort to encourage and support the person to make their own decision. If a lack of capacity is established, it is still important that staff involve the person as far as possible in making decisions.
- **Unwise decisions** – People have the right to make what others might regard as unwise or eccentric decisions. Everyone has his or her own values, beliefs and preferences, which may not be the same as those of other people. Staff cannot treat people as lacking capacity for that reason.
- **Best Interests** – Anything done for or on behalf of a person who lacks mental

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

capacity must be carried out in their best interests

- **Least restrictive option** – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

The University Hospitals of Morecambe Bay NHS Foundation Trust's 'Mental Capacity Act (2005)' and Deprivation of Liberty Standards' policies are available on the Trust Procedural Document Library (see Section 6 for links).

### Capacity to Consent:

The Mental Capacity Act<sup>3</sup> describes the following two-stage test to determine capacity:

- Is there an impairment of, or disturbance in the functioning of the person's mind or brain? If so,
- Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?

A person is considered able to make a decision if he/she is able to:

- Understand the information relevant to the decision
- Retain that information
- Use or weigh that information as part of the process of making the decision, or
- Communicate his/her decision (whether by talking, using sign language or any other means).

University Hospitals of Morecambe Bay NHS Foundation Trust templates for assessing capacity can be found on the learning disability page of the trust's intranet.

If staff need support regarding the application of the legal requirements of the Mental Capacity Act (2005)<sup>3</sup> they should contact the clinical nurse specialist for learning disabilities and/or the community learning disability team.

#### 4.7.2.2 Care and Treatment

A third party cannot legally give or withhold consent to care and treatment, on behalf of another adult and should **never** be asked to sign a consent form on behalf of another person unless they have valid Lasting Power of Attorney for Health and Welfare or are a Personal Welfare Deputy appointed by the Court of Protection, and even so the treatment must be in the patient's best interests.

Health professionals proposing care or treatment for an individual have a professional responsibility to provide information in an accessible format to empower individuals to make an informed decision where possible.

They are then responsible for determining whether the individual has capacity to give consent to the treatment or procedure in accordance with the Mental Capacity Act (2005)<sup>3</sup> and document accordingly.

#### 4.7.2.3 Advanced decisions, lasting power of attorney and/or court of protection

Health care professionals have a duty to determine whether the individual has previously made an advanced decision regarding care and treatment. Families, carers and their local authority or active social worker may be able to assist with this. All staff also have a

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

responsibility to establish whether a third party has a lasting power of attorney or under court of protection. All evidence must be seen, copied and filed with the individual's notes.

#### 4.7.2.4 Determining best Interests

Where it has been determined that the individual lacks capacity to consent all care and treatment must be in that person's best interests and be the least restrictive option. Staff should consult relatives and carers about the patient's best interests; if there is no significant individuals to consult then an independent mental capacity advocate (IMCA) must be consulted. The trust's template for recording best interest decisions can be found on the learning disability page of the trust's intranet.

#### 4.7.2.5 Resolution of disputes

If consensus cannot be reached there are a number of options, which may be explored, including:

- Involvement of an independent advocate, to act on behalf of the person lacking capacity (Independent Mental Capacity Advocate I.M.C.A)
- Obtaining a second opinion (for medical treatment)
- Holding a formal or informal case conference
- Attempting mediation (though reaching consensus will not necessarily determine best interests of the person lacking capacity)

If following thorough discussion with all involved there is still significant disagreement regarding proposed treatment or non-treatment of an individual, hospital staff should discuss their concerns with the relevant department lead. Contact should be made with the trust's safeguarding team, it may then be decided that legal advice is necessary via the trust's legal team.

The courts have identified certain circumstances when healthcare professionals or others must make an application to the Court of Protection.

These are:

- Where there is serious uncertainty about the patient's capacity to consent, or about their best interests
- or**
- Where there is serious unresolved disagreement between a patient's family and health professionals.

The Mental Capacity Act 9E Practice Directive<sup>9</sup> instructs that proposed serious medical treatment where there are potentially serious consequences to the patient should be brought before the Court of Protection for judgement. See link for more detail:

<https://www.judiciary.gov.uk/wp-content/uploads/2015/06/copd-pd-9e-serious-medical-treatment.pdf>

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

## 4.8 Compliments, Comments, Concerns and Complaints

Individuals, families and/or carers should be encouraged to raise concerns, compliments, and comments, with the relevant ward or clinic staff. When this is not possible, staff should direct patients and/or carers to access the Patients Advice and Liaison Service (PALS) and/or use the hospital's complaints procedure.

## 4.9 Preparation for Hospital Visits, Admissions and Discharges

See Appendix 1 – Learning Disability Hospital Pathway.

Coming into hospital can be a stressful time; prior to admission support can be provided by the Community Learning Disability Team and the Hospital Liaison Learning Disability Nurse. Planning treatment and visiting ward/depts. prior to a planned admission can help to avoid unnecessary distress and anxiety and ensure the patient has a positive health outcome. This information can be formulated in an individualised admission support plan and/or hospital passport.

Staff should work with individuals, families and/or carers to establish the preferred communication method and adjust information accordingly. This may include the use of pictures, symbols, photographs and social stories.

An aspect of the admission process should be identifying reasonable adjustments. Reasonable adjustments should be agreed prior to planned admissions this may include longer appointment times, environmental changes for example quiet rooms, equipment requirements such as hoists, additional support needs for aspects of daily living and specific communication needs. Consideration should be given to combining procedures, if required, wherever possible. During anaesthesia, there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient. This will require consideration of consent / best interests. Staff should also make sure transport has been considered.

Staff must ensure that all discharge information is in a format that the individual understands and that the person has the support and resources they need to implement actions in the discharge plan.

As part of the discharge process the principles of the Mental Capacity Act<sup>3</sup> must be considered. If the person is deemed to lack capacity it is good practice to involve all relevant individuals involved in the persons care for example family, care providers, allied health professionals and social workers if it is in the person's best interest.

The discharge process should include an assessment of the individual's independent living skills and consider whether current support and environment provisions are still appropriate.

Careful consideration of the individual's ability to manage new treatments and advice given and whether support will be required for this.

Hospital pharmacies provide a comprehensive list of "easy read" documents covering specific medications. They can be accessed and printed from the dispensary on request.

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

Ward staff need to ask pharmacy for a 'Medicine Card'. This will automatically involve the pharmacist in the patient's discharge care and in preparing information specifically for individual patients. There is currently no facility to provide audio guides but pharmacy could e-mail a link, if this was appropriate, to a patient or carer.

#### 4.10 Sharing Information

All patients have a right to privacy and control of information about themselves. If the person is deemed to lack capacity to share information then the principles of the Mental Capacity Act<sup>3</sup> must be considered. If the person is deemed to lack capacity it is good practice to involve all relevant individuals involved in the persons care for example family, care providers, allied health professionals and social workers if it is in the person's best interest.

#### 4.11 Additional Support

Due to the complex care needs of some individuals additional support may be required when in hospital. The responsibility for providing medical and nursing care remains with the hospital.

When it is identified an individual requires additional support with communication, managing stress and anxiety and keeping safe discussion must be held with the ward manager to ascertain and agree additional support needs and how this will be provided for example hospital staff, family or care provider.

#### 4.12 Funding issues if additional support in hospital is required (see appendix 2)

If additional support is required the ward manager/clinical lead must identify a specific need e.g. the patient may require their own familiar staff to support with aspects of daily living such as person care, feeding taking medication, or specific support with receptive and expressive communication and provide a clear rationale for the request e.g. the patient needs predictability in facilitating care and responds best to a familiar member of staff from home OR the patient may require support from their own staff to help them understand and express themselves . Specific funding for this will be determined on an individual basis by the Assistant Director of Operations and Performance and Assistant Chief Nurse. Support in establishing additional needs and requesting additional support can be obtained from the Trust Clinical Nurse Specialist for Learning Disabilities.

People with fully funded health packages at home are *likely* to be supported in hospital if necessary by their own carers as part of their care package.

People with joint funded packages at home *may* be supported in hospital depending on particular issues some additional support in excess of their current care package will need to be funded by the Hospital.

People with fully funded social care packages are *unlikely* to be supported by their carers whilst in hospital, and additional support needs will need to be funded by the Hospital.

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
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## 4.13 Responsibilities

### 4.13.1 General Staff Responsibilities

The wards at University Hospitals of Morecambe Bay NHS Foundation Trust are managed by a matron, sister or charge nurse. Teams of nurses provide 24-hour individualised care to meet the specific care needs of people with learning disabilities. In addition to nursing staff, as with all patients, a person with learning disabilities will meet doctors on a regular basis. The doctor may also ask for Physiotherapists, Occupational Therapists, Dieticians and Speech Therapists and other allied health professionals to assist in the individual's care.

Following admission to hospital, the patient, family or their carer should give their Hospital Passport if available to the nurse in charge on the ward during the admission process. If the patient doesn't currently have a Hospital Passport they can be encouraged to complete one, assistance can be obtained from the Clinical Nurse Specialist for Learning Disabilities or a member of the Community Learning Disability Teams as appropriate (see Appendix 3 - Useful Contacts). The nurse in charge will liaise with the patient, family and or their carer to discuss their individual health requirements (apply the principles of the Mental Capacity Act 2005<sup>3</sup> - see Section 4.7.2).

The Matron or Senior Nurse, during daytime hours and the Clinical Site Manager or Bleep holder at evenings and weekends will be the point of contact for any patient either admitted or using outpatient/day surgery facilities.

### 4.13.2 Line Manager Responsibilities

The ward line manager is responsible for ensuring that they and their staff are aware of this guideline and that audits are undertaken to ensure compliance.

## 4.14 Acknowledgements

This guideline was influenced by work carried out by the Learning Disability Service in Kingston Primary Care Trust.

It has been reviewed by representatives from:

- University Hospitals of Morecambe Bay NHS Foundation Trust
- Cumbria Partnership NHS Foundation Trust
- Lancashire Care NHS Foundation Trust
- Service user groups
- Local care providers
- Families and carers

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

5. ATTACHMENTS	
Number	Title
1	Learning Disability Hospital Admission Pathway
2	Funding of support if required by adults with learning disabilities on admission to hospital
3	Useful Contacts
4	Equality & Diversity Impact Assessment Tool

6. OTHER RELEVANT / ASSOCIATED DOCUMENTS	
Unique Identifier	Title and web links from the document library
Corp/Pol/033	Mental Capacity Act (2005) <a href="http://uhmb/cs/tpdl/Documents/CORP-POL-033.docx">http://uhmb/cs/tpdl/Documents/CORP-POL-033.docx</a>
Corp/Pol/034	Deprivation of Liberty Standards <a href="http://uhmb/cs/tpdl/Documents/CORP-POL-034.docx">http://uhmb/cs/tpdl/Documents/CORP-POL-034.docx</a>

7. SUPPORTING REFERENCES / EVIDENCE BASED DOCUMENTS	
References in full	
Number	References
1	Great Britain (2010) Equality Act 2010. Available at: <a href="http://www.legislation.gov.uk/ukpga/2010/15/contents">http://www.legislation.gov.uk/ukpga/2010/15/contents</a> (accessed 17.9.18)
2	NHS England (2016) Accessible Information Standard. Available at: <a href="https://www.england.nhs.uk/ourwork/accessibleinfo/">https://www.england.nhs.uk/ourwork/accessibleinfo/</a> (accessed 17.9.18)
3	Great Britain (2005) Mental Capacity Act 2005. Available at: <a href="http://www.legislation.gov.uk/ukpga/2005/9/contents">http://www.legislation.gov.uk/ukpga/2005/9/contents</a> (accessed 17.9.18)
4	Department of Health (2009) Valuing people now. Available at: <a href="http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/p/rod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf">http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/p/rod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf</a> (accessed 17.9.18)
5	Healthcare Improvement Scotland (2006) Promoting access to healthcare for people with a learning disability - a guide for frontline NHS staff. Available from: <a href="http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/promoting_access_to_healthcare.aspx">http://www.healthcareimprovementscotland.org/previous_resources/best_practice_statement/promoting_access_to_healthcare.aspx</a> (accessed 17.9.108)
6	DH (2001) Consent - what you have a right to expect: a guide for parents. Available from: <a href="http://webarchive.nationalarchives.gov.uk/20120106011230/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005202">http://webarchive.nationalarchives.gov.uk/20120106011230/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005202</a> (accessed 17.9.18)
7	CQC (2017) Gillick competency and Fraser guidelines. Available from: <a href="https://www.cqc.org.uk/guidance-providers/gps/nigels-surgery-8-gillick-competency-fraser-guidelines">https://www.cqc.org.uk/guidance-providers/gps/nigels-surgery-8-gillick-competency-fraser-guidelines</a> (accessed 17.9.18)
8	Office of the Public Guardian (2013, updated 2016) Mental Capacity Act 2005 Code of Practice. Available from: <a href="https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice">https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice</a> (accessed 17.9.18)
9	Great Britain (2015) Court of Protection: Practice Direction 9E: Applications relating to serious medical treatment. Available from: <a href="https://www.judiciary.uk/publications/practice-direction-9e-applications-relating-to-">https://www.judiciary.uk/publications/practice-direction-9e-applications-relating-to-</a>

University Hospitals of Morecambe Bay NHS Foundation Trust	ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021
Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs	
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version	

[serious-medical-treatment-effective-from-1-july-2015/](#) (accessed 17.9.18)

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Mencap (2007) Death by indifference: following up the “Treat me right!” report. Available at: <https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf> (accessed 17.9.18)

Mencap (2012) Death by indifference: 74 deaths and counting. Available at: <https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf> (accessed 17.9.18)

NHS England (2012) Getting it right for people with learning disabilities. Available at:

<http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Documents/NHS-England-Getting-it-right-for-people-with-learning-disabilities-epublication.pdf> (accessed 17.9.18)

NHS England (2015) Transforming care for people with learning disabilities – next steps.

Available at: <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf> (accessed 17.9.18).

## 8. DEFINITIONS / GLOSSARY OF TERMS

Abbreviation or Term	Definition

## 9. CONSULTATION WITH STAFF AND PATIENTS

Enter the names and job titles of staff and stakeholders that have contributed to the document

Name	Job Title	Date Consulted
Brian Evans	Clinical Nurse Specialist For learning Disabilities, UHMBT	
Linda Turner	Senior Community Learning Disability Nurse Specialist, CPFT	
Sarah Norris	Community Learning Disability Nurse, Lancashire Care.	
Rebecca Dickinson	Children’s Community Learning Disability Nurse, CPFT	
Nicola Bruff	Children’s Community Learning Disability Nurse, CPFT	
Annalee Stevens	Student Nurse, University of Cumbria.	
Charlotte Patterson	Student Nurse, University of Cumbria.	

University Hospitals of Morecambe Bay NHS Foundation Trust	ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021
Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs	
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version	

<b>10. DISTRIBUTION PLAN</b>	
Dissemination lead:	Brian Evans
Previous document already being used?	Yes
If yes, in what format and where?	
Proposed action to retrieve out-of-date copies of the document:	
<b>To be disseminated to:</b>	
Document Library	
Proposed actions to communicate the document contents to staff:	Include in the UHMB Friday Corporate Communications Roundup or Weekly News. New documents uploaded to the Document Library.

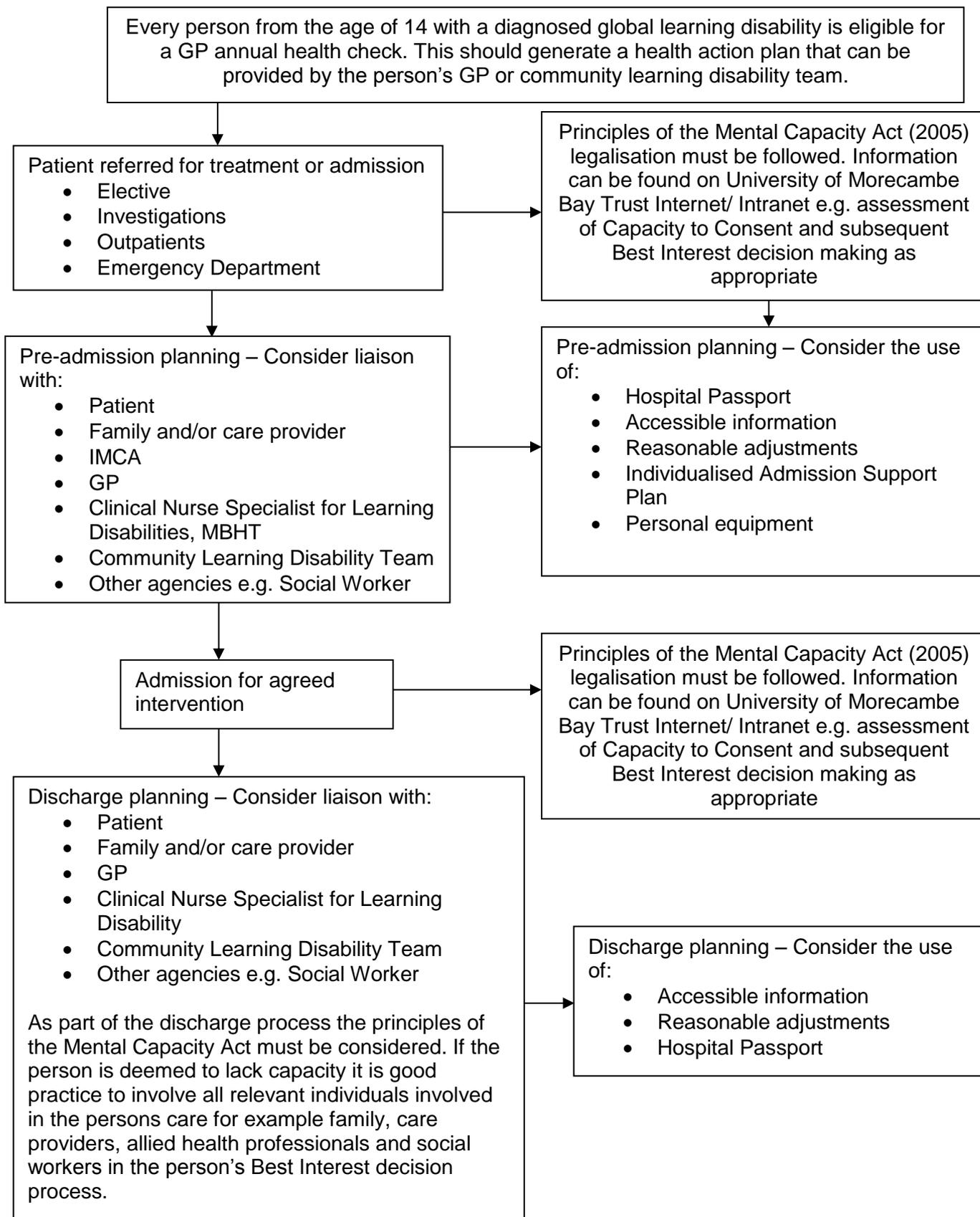
<b>11. TRAINING</b>		
Is training required to be given due to the introduction of this procedural document? No		
Action by	Action required	Implementation Date

<b>12. AMENDMENT HISTORY</b>				
Version No.	Date of Issue	Section/Page Changed	Description of Change	Review Date
1	February 2015		Ratified	
2	June 2017	All	Reviewed and updated legislative information and evidence based practice	01/03/2021

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

## Appendix 1

# LEARNING DISABILITY HOSPITAL ADMISSION PATHWAY



University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version		

## Appendix 2 – Funding of support if required by adults with learning disabilities on admission to hospital.

Currently there are no specific arrangements for providing additional funding for children who are admitted to hospital. It is anticipated that in the majority of cases parents/carers will wish to take on this role however it is important parents/carers are given ample opportunity to have regular breaks to ensure they don't experience 'burn out'.

### Introduction

Clarifies the funding arrangements for specific staff support, if required by an individual with a learning disability during an admission to hospital. It also recommends good practice in terms of the provision of that support.

These arrangements have been agreed by University Hospitals of Morecambe Bay NHS Foundation Trust, NHS Cumbria, the Cumbria Partnership NHS Trust, and the Provider Forum for Learning Disabilities.

### Principles

- People with learning disabilities have a right to the same level of medical and nursing care as that provided to the general population. This care must be person-centred, flexible and responsive to the individual's specific needs. Diagnosis or treatment should take account the specific needs generated by the individuals learning disability.
- The responsibility for medical and nursing care provided to people with learning disabilities will remain with the Hospital at all times during the patient stay.

### Background

The Government White Papers "Valuing People" (DoH 2001) and "Valuing People Now" (DoH 2010)<sup>1</sup> identify specific healthcare aims:

"To enable people with learning disabilities to access a health service designed around their individual need, with fast and convenient care delivered to a consistently high standard and with additional support where necessary".

In addition, one of the Health Action points states

"NHS should ensure that all mainstream hospital services are accessible to people with learning disabilities".

The White Papers goes on to say:

"Mainstream secondary health services must also be accessible for people with learning disabilities. There must be no discrimination. Support will be needed to help people with learning disabilities admitted to a general hospital for medical or surgical treatment to help them understand and co-operate in their treatment. The NHS will ensure that all its procedures comply with the Equality Act (2010)<sup>2</sup> and that its staff recruitment and training practices are also fully compliant".

### Funding Arrangements

It is the responsibility of the NHS to ensure people with a learning disability have access to the same standard of care as the rest of the population during an admission to an acute hospital this includes making all reasonable adjustments (Equality Act 2010<sup>2</sup>) to ensure care is person-centred and effective.

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

For some individuals with a learning disability their complex care needs may mean they require additional staffing support during their stay in hospital. The rationale for this additional staffing may include the need for support from experienced and predictable known staff with their receptive and expressive communication or support from a predictable and familiar staff for aspects of their daily living. This may be due to cognitive ability, mental capacity, specific sensory needs, mental health problems, historical issues or difficulties to support due to their behaviour.

Where possible the assessment of individual requirements for additional specific staffing support whilst in hospital should be undertaken by the ward manager/clinical lead, with support from the Trust Clinical Nurse Specialist for Learning Disabilities in liaison with any relevant healthcare professionals within the community learning disability team, or the person who best knows the patient (in line with local agreements), the outcome of the assessment should be recorded and a request for additional support submitted to the Assistant Director of Operations and Performance and Assistant Chief Nurse for authorisation and the outcome shared at the earliest opportunity with the carer provider management and staff to provide time to organise additional support requirements. The agreed additional external support must be monitored and reviewed regularly and must be for the identified and agreed specific care need, when the need for the additional external support is no longer required the ward manager/clinical lead must notify the care provider of the date/time the additional care funding will cease. Funded additional care provision must be agreed in writing with the care provider manager.

For day care admissions to hospital, it is an expectation that any additional support required for the patient would be part of their care package or arranged through the Adult Social Care Team. In these cases, appropriate planning should have taken place, to ensure that hospital staff are aware of the specific needs of an individual patient, and agreement as to any level of extra staffing support would have been reached. Support with admission planning can be obtained from the Trust Clinical Nurse Specialist for Learning Disabilities.

In the case of an emergency admission, it would be an expectation that the care provider support the individual with any additional care needs.

In the event that any issues should arise regarding facilities for carers of people with learning disabilities during a hospital admission these should be brought to the attention of Patient Advice and Liaison (PALS).

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		

### Appendix 3: Useful Contacts

Clinical Nurse Specialist Learning Disabilities – 01229 406793 or 07813536877

Children’s Community Learning Disability and Behaviour Support Service Cumbria - 01229 404693

Children’s Community Learning Disability Team – Lancaster – 01772 644644 / 01524 550650

CAMHS - South Cumbria - 01229 402696

CAMHS - Lancaster and Morecambe – 01524 550650

Adult Community Learning Disability Team – Cumbria – 01229 404524

Adult Community Learning Disability Team – Lancashire – 01524 550330

Adult Autism Diagnostic Service – Cumbria – 01229 404521

Children’s Services – Barrow-in-Furness – 01229 408100

Children’s Services – Kendal – 01539 713562

Children’s Services – Lancaster – 0300 1236701

Adult Social Care – Barrow-in-Furness – 01229 407446

Adult Social Care – Kendal – 01539 713378

Adult Social Care – Lancaster – 0300 123 6720

People First – Advocacy Service – Barrow-in-Furness – 01229 811278

Caritas Care - Advocacy Service – Lancaster – 01772 732313

Furness General Hospital – Barrow-in-Furness – 01229 870870

Westmorland General Hospital – Kendal – 01539 732288

Royal Lancaster Infirmary – Lancaster – 01524 65944

Queen Victoria Hospital – Morecambe – 01524 518965

Cumbria Partnership Specialist Dental Service – Barrow-in-Furness - 01229 835234

Cumbria Partnership Specialist Dental Service - Kendal – 01539 716822

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		



### Equality Impact Assessment Form

Department/Function	Corporate- Learning Disabilities, Autism and Complex Needs			
Lead Assessor	Brian Evans- Clinical Nurse Specialist for learning Disabilities			
What is being assessed?	Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs			
Date of assessment	19/07/2018			
What groups have you consulted with? Include details of involvement in the Equality Impact Assessment process.	Equality of Access to Health Group	<input checked="" type="checkbox"/>	Staff Side Colleagues	<input type="checkbox"/>
	Service Users	<input type="checkbox"/>	Staff Inclusion Network/s	<input type="checkbox"/>
	Personal Fair Diverse Champions	<input type="checkbox"/>	Other (Inc. external orgs)	<input checked="" type="checkbox"/>
	Please give details: Community children and adult learning disability teams in South Cumbria and North Lancashire, People First Advocacy Group, South Cumbria.			

1) What is the impact on the following equality groups?		
Positive:	Negative:	Neutral:
<ul style="list-style-type: none"> <li>➤ Advance Equality of opportunity</li> <li>➤ Foster good relations between different groups</li> <li>➤ Address explicit needs of Equality target groups</li> </ul>	<ul style="list-style-type: none"> <li>➤ Unlawful discrimination, harassment and victimisation</li> <li>➤ Failure to address explicit needs of Equality target groups</li> </ul>	<ul style="list-style-type: none"> <li>➤ It is quite acceptable for the assessment to come out as Neutral Impact.</li> <li>➤ Be sure you can justify this decision with clear reasons and evidence if you are challenged</li> </ul>
Equality Groups	Impact (Positive / Negative / Neutral)	Comments
Race (All ethnic groups)	Positive	<ul style="list-style-type: none"> <li>➤ Provide brief description of the positive / negative impact identified benefits to the equality group.</li> <li>➤ Is any impact identified intended or legal?</li> </ul> Advance Equality of opportunity
Disability (Including physical and mental impairments)	Positive	Foster good relations between different groups Address explicit needs of Equality target groups
Sex	Positive	Address explicit needs of Equality target groups
Gender reassignment	Positive	Address explicit needs of Equality target groups
Religion or Belief	Positive	Address explicit needs of Equality target groups
Sexual orientation	Positive	Address explicit needs of Equality target groups
Age	Positive	Address explicit needs of Equality target groups
Marriage and Civil Partnership	Positive	Address explicit needs of Equality target groups
Pregnancy and maternity	Positive	Address explicit needs of Equality target groups

University Hospitals of Morecambe Bay NHS Foundation Trust	ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021
Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs	
Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version	

Other (e.g. caring, human rights)	<b>Positive</b>	Address explicit needs of Equality target groups
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2) In what ways does any impact identified contribute to or hinder promoting equality and diversity across the organisation?	The policy does not have any impact that contributes to or hinders promoting equality and diversity
--	---

3) If your assessment identifies a negative impact on Equality Groups you must develop an action plan <b>to avoid discrimination and ensure opportunities for promoting equality diversity and inclusion are maximised.</b>
➤ This should include where it has been identified that further work will be undertaken to further explore the impact on equality groups
➤ This should be reviewed annually.

Action Plan Summary

Action	Lead	Timescale

*This form will be automatically submitted for review for Policies and Procedures once approved by Policy Group. For all other assessments, please return an electronic copy to [EIA.forms@mbht.nhs.uk](mailto:EIA.forms@mbht.nhs.uk) once completed.*

University Hospitals of Morecambe Bay NHS Foundation Trust		ID No. Corp/Guid/086
Version No: 2	Next Review Date: 01/03/2021	Title: Access to Hospital Services for Children and Adults with Learning Disabilities, Autism and Complex Needs
<i>Do you have the up to date version? See the Trust Procedural Document Library (TPDL) for the latest version</i>		