The Walton Centre NHS
NHS Foundation Trust

Excellence in Neuroscience

Learning Disability Policy (care and treatment of a people with a learning disability)

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Executive Summary

The Walton Centre NHS Foundation Trust(WCFT) is committed to providing a responsive service which recognises the needs of those patients who may be disadvantaged in accessing care and treatment due to disability or other health inequalities.

The Equality Act 2010 (incorporating the Disability Discrimination Act 2005) puts the responsibility on all public services to ensure that no discriminatory practices exist within their organisation and that services meet the needs of the individual. Hospitals have a clear 'duty of equality'. This does not mean treating everybody the same but rather that all hospitals must make 'reasonable adjustments' to meet the needs of disabled people. This policy sets out the standards of care the WCFT wishes to provide to people with a learning disability and/or autism that access our services.

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1. Introduction

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The Parliamentary and Health Service Ombudsman's and the Local Government Ombudsman's report 'Six Lives' (2009) and the Michael report 'Healthcare for All' (2008) made recommendations for the care of people with learning disabilities and this policy has been created to aid compliance with these recommendations.

The Autism Act (2009) and the Autism Strategy (2010) together with the NICE Guideline for Autism (2014) dictate that statutory services make the necessary adjustments to improve accessibility for people with Autism.

To enable the highest standard of care to be achieved, this policy sets out the guidelines to ensure that patients with a learning disability and/or autism (PWLD/A) will have their specific needs identified and met, ensuring reasonable adjustments are made to enable appropriate services to be delivered in an acceptable manner.

Evidence shows that health needs of PWLD/A are greater than those of the general population and there are several key issues they face when accessing the services of acute hospitals (Valuing People, DH 2001; Valuing People Now, DH 2009; Death by Indifference, Mencap, 2007; 74 Deaths and Counting, Mencap, 2012 and the CIPOLD Report, 2013). The WCFT recognises these issues and is committed to 'getting it right' when meeting the needs of PWLD/A.

This policy sets out the standards of care the WCFT wishes to provide to people with a learning disability and/or autism that access our services.

1.1. Background Information

People with learning disabilities (LD) often experience extreme health inequalities, poor health outcomes, and poor access to healthcare despite their greater health problems and needs. The guiding principles that underpin this policy are those directed through statute Law; Common Law Judgements and Department of Health policies as follows:

- The Treat Me Right report produced by Mencap in 2004 concluded that an inquiry made into the deaths of people with LD would not only evidence the cause of death but could be used as leverage for improving the delivery of health services.
- The Disability Rights Commission Report published in 2006 considered it "alarming" that so little had been done in implementing the recommendations made in The Treat Me Right Report by people with powers to do so; and in 2007 they criticised the lack of strategic change and lack of priority despite their previous report.
- Death by Indifference (2007) detailed six case studies where young people with LD all died in avoidable circumstances in acute hospitals and suggested that people

with LD their families and Carers were facing “institutionalised discrimination” in healthcare services.

- The response to this report was an Independent Inquiry into access to health care for people with LD and this culminated in Healthcare for All (2008) which set out key lessons learned, and several recommendations were made for acute trusts to follow. Sir Michael reported on available evidence of “a significant level of avoidable suffering and a high likelihood that deaths are occurring which could be avoided”.
- The Equality Act (2010) protects against discrimination and requires all services to make reasonable adjustments where needed.
- The above have all been key reports which have contributed to a call for a confidential enquiry into premature deaths of people with LD. The Confidential Enquiry into premature deaths of people with learning disabilities (CIPOLD) study (2013) revealed that the quality and effectiveness of both health and social care given to people with LD are deficient in a number of ways. Further key recommendations are made to prevent premature deaths for this patient group and this is now a priority for the NHS.
- In June 2015, NHS England commissioned the National Learning Disability Mortality Review Programme led by the University of Bristol, to review and learn from deaths of people with a learning disability with the aim of improving services, care and support nationally. The three-year project will investigate the causes of premature mortality for people with a learning disability and will develop a strategy to reduce this inequality.
- The Government and NHS England have also committed to reducing the number of people with a learning disability who are placed in inpatient services. NHS England’s Transforming Care programme intends to improve the quality of life of those with learning disabilities by substantially reducing the number of people placed in hospital, reducing the length of time those admitted spend there, and enhancing the quality of both hospital and community settings.
- In 2015, NHS England, in partnership with local government leaders, published a national action plan to develop community services and close inpatient facilities for people with a learning disability and/or autism. The Building the Right Support1 plan aims to shift money from inpatient services to the community and reduce the use of inpatient beds by 35% - 50% in the next three years.
- From June 2016, the Department of Health will publish independently assured, ratings of the quality of healthcare offered to people with learning disabilities in all CCG areas, to highlight variations and to allow rapid action to be taken when improvement is needed

2. Scope

This policy applies to all staff working at The Walton Centre NHS Foundation Trust involved in providing support, services or direct care to individuals with learning disabilities and their carers

Everyone within WCFT has a responsibility for and is committed to ensuring all people with a learning disability and/or autism (PWLD/A) receive the correct care and support required regardless of any associated problem relating to their LD and/or Autism.

3. Definitions

3.1. Learning Disability

A learning disability affects the way that someone communicates and understands information. This means that someone may have difficulties:

- understanding new or complex information;
- learning new skills; and
- coping independently

It is estimated that around 1.5 million people in the UK have a learning disability, and around 350,000 people have a severe learning disability. A learning disability can affect children and adults, although children and young people with a learning disability may also have special educational needs.

The broad term 'learning disability' can cover a spectrum of conditions, from a mild learning disability where someone can manage independently but might take longer to learn new skills, to a profound and severe learning disability where an individual may need substantial care and support with every aspect of their life.

Learning Disability is divided into four classification groups: Mild, Moderate, Severe and Profound. The diagnosis of profound and multiple learning disability (PMLD) is used when the individual has more than one impairment (i.e. sensory, physical, complex health needs, mental health issues) with the most significant being a learning disability. People with PMLD will require support from a carer/s to assist them with most areas of everyday life, such as eating/drinking, washing/dressing and going to the toilet.

Learning Disability does not include:

- The development of intellectual, social or adaptive impairments after the age of 18
- Brain injury acquired after the age of 18
- Complex medical conditions that affect intellectual and social/adaptive functioning: e.g. dementias; Huntington's Disease
- Specific learning difficulties e.g. dyslexia, dyspraxia, dyscalculia, literacy or numeracy problems or delayed speech and language development.

The term "***Learning Difficulties***", that is often used in educational services to describe people with specific learning problems, does not indicate that a person has a learning disability as defined above, however it is important to note that these two terms are often used interchangeably to indicate that a person has a learning disability.

3.2. Autism

The Autism Act (2009), Autism Strategy (2010) and NICE Autism Guideline (2014) identify that a significant proportion of people with autism across the whole spectrum experience social and economic exclusion. The condition has been noted as '*frequently overlooked by health, education and social care professionals, which in turn creates barriers to accessing the support and services needed'*.

The NICE guideline offers the best practice advice on the person-centred care of people with autism. It highlights that support and care 'should consider peoples' individual needs and preferences'. Additionally, it states 'people with autism should have the opportunity to make informed decisions about their care, in partnership with healthcare professionals'. Where individuals who are 16 or over lack capacity, decisions are made in the individual’s best interests according to the statutory requirements set out through the Mental Capacity Act 2005.

3.3. Autistic Spectrum Disorder

Autistic Spectrum Disorder (ASD) is the term that is used to describe a group of disorders, including Autism and Asperger’s syndrome. The word ‘spectrum’ is used because the characteristics of the condition vary from one person to another. Autism is a lifelong developmental disability that first appears during infancy or childhood and affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. It is estimated that up to 45% of individuals with autism may also have a learning disability. Those who have Asperger’s syndrome tend to have average, or above average, intelligence, but still have difficulty making sense of the world and interacting with others.

Autism can co-exist with many other diagnoses including depression, social anxiety, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, Tourette’s syndrome, developmental coordination disorder, eating disorders, personality disorders and psychosis. A number of genetic syndromes are also associated with autism such as Tuberous Sclerosis, Fragile X, Angelman syndrome, Rett syndrome and Turner syndrome.

People with ASD experience three main difficulties,

- Social Interaction - difficulty with social relationships often appeared distant or detached.
- Social Communication – difficulty with understanding verbal and non–verbal communication, body language, gestures, facial expression, tone of voice.
- Social Imagination – difficulty in the development of play and imagination with others. People with ASD often have a limited number of activities that are possibly copied and performed rigidly and repetitively.

4. Duties

4.1. Director of Nursing & Governance is responsible for:

- ensuring the WCFT 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 because of a learning disability and/or autism
- assuring the WCFT Board and public that there are policies, processes and monitoring systems in place so that WCFT is compliant in its obligations under the Care Act, Equality Act, quality/safety standards and Government requirements

4.2. Safeguarding Matron is responsible for:

- the Safeguarding Matron key role is to lead in the improvement of effective, accessible quality care delivery within the WCFT which is responsive to the needs of PWLD/A
- The Safeguarding Matron is responsible for providing highly specialist leadership, guidance and advice that supports the development of acute hospital service good practice. This will be through close collaborative working with healthcare and multi-agency professionals
- the Safeguarding Matron will lead on the revision and support the embedding of the Learning Disability Policy

- The Safeguarding Matron should be made aware of all PWLD/A who are admitted to the WCFT.
- The Safeguarding Matron will support the advocacy for the patient in relation to any reasonable adjustments that may be required to meet the needs of the PWLD/A.
- The Safeguarding Matron will work closely with the Outpatient Departments to ensure PWLD/A and their families/carers are supported whilst accessing these services.

4.3. Clinical Staff are responsible for:

- all clinical staff are required to ensure that the needs of PWLD/A are met through individual assessment and care planning that considers the views of the patient and family member/carer and the patient's Health/Hospital Passport and personal Health Action Plan if the patient has one
- the Health Passport provides clear and concise information in an easy to understand format regarding the person's support needs
- the Health Action Plan also belongs to the PWLD/A and should accompany the person for all hospital appointments and admissions
- clinical staff providing care and treatment have a responsibility to ensure that the PWLD/A 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/pictures as appropriate to the ability of the patient
- clinical staff should always act as the patient's advocate ensuring that they are given information about their condition and/or treatment in a way that they can understand to make decisions within the limits of their capacity. It is important that clinical staff acknowledge that family members/carers understand the PWLD/A best and work in partnership with them to ensure that the communication needs of the individual are met

4.4. All Staff

- All staff are responsible for ensuring that PWLD/A can access care and treatment at the Trust. In doing this staff must ensure that the needs of the patient are accommodated in terms of equal and timely access to all services provided
- All staff must recognise that PWLD/A may have needs related to their disability and that consideration must be given to meeting those needs when delivering other services
- Every staff member has a responsibility to act as an advocate for PWLD/A 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.
- Any member of staff, including volunteers that encounter a PWLD/A must be aware of what this means, how they should be treated and from where they can find more information and help

4.5. Learning Disabilities Champions

- The WCFT has a network of Learning Disabilities Champions in most wards and Departments to support colleagues to meet the needs of PWLD/A. All wards, departments and clinical settings should have an identified champion, who will receive additional training and supervision to support their role. Champions support the care planning and care of a PWLD/A and cascade information to their colleagues.

5. Process

5.1. Identification of patients

An electronic alert flag is available on both the Patient Administration System (PAS) and EP2 for ‘Learning Disabilities’ and ‘Autism’. If patients are not flagged in this way, these alerts can be added by staff in the PACS team and ward clerks. The alert is used to identify that the patient has a learning disability and/or autism and should trigger reasonable adjustments required by that individual.

5.2. Communication and Patient Information

PWLD/A frequently have difficulties with communication. This may include problems with expression, articulation, comprehension and coping with social situations. This may mean they appear more able than they are. Expression and comprehension do not always function at the same level. PWLD/A often have a problem understanding complex sentences and abstract concepts and consideration should be given to the context of the information given and the format used. Difficulties are often compounded by being in an unfamiliar environment and being cared for by unfamiliar people.

An individual’s capacity to understand and communicate can be affected by several factors, including anxiety, pain and distress, unfamiliar people and environments. PWLD/A may also be unable to describe adequately their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell.

Feeling unwell or in pain can cause fear, confusion and distress and potentially lead to difficult behaviour and poor co-operation. The health care professional can help prevent problems that may arise from communication difficulties by gaining information about the person’s communication needs from the family or carers, including the following:

- Likes and dislikes.
- Level of comprehension.
- How he/she indicate anxiety/distress.
- What calms / relaxes him/her.
- How he/she indicate pain or discomfort.
- How he/she communicates basic needs e.g. thirst, hunger, toilet.
- How to best prepare him/her for examination, procedures, touch etc.
- Giving information in small chunks appropriate to the level of understanding.
- Using short and terminology free sentences.
- Allowing plenty of time for processing of information and be prepared to repeat information.
- Being prepared to give information in other formats e.g. images, pictures, videos, objects etc.
- Using basic non-technical vocabulary.
- Being prepared to demonstrate procedures first.

5.3. Reinforcement of information

PWLD/A may have difficulty in understanding information presented only as written text and therefore information in easy read format or other media should be provided to promote understanding and to enable PWLD/A to make informed choices about their care and treatment.

The Safeguarding Matron is able to assist in the development of accessible information. There are several ‘easy-read’ resources available about a number of health issues, treatment methods and physical examinations available via the website: http://easyhealth.org.uk/

There is also a ‘Hospital Communication Book’ available as a laminated copy on each ward. This is an excellent resource that contains useful information, advice and a range of communication techniques and strategies such as signs & symbols on how to communicate effectively with people who have difficulties with communication.

It is most important to check that any information given has been understood and, if it is helpful for the PWLD/A to have a familiar person with them, try to arrange this prior to speaking to the patient on your own.

Some PWLD/A do not communicate verbally and rely on other methods such as gestures, pointing or facial expressions to communicate their needs. In addition to asking the family carer/support workers, staff should utilise the patient’s Health/Hospital Passports and read the communication information within it. Communication can also be supported with the use of simple picture symbols, also through the use of sign language such as Makaton and British Sign Language (For more information, see the Hospital Communication Book

Some people may utilise their own communication tools, for example: a ‘Communication Passport’ or communication book which is an individualised communication tool (usually a folder which contains photographs and symbols). There are also a few other specialists speaking communication aids available which some individuals may use.

Procedures should never be carried out quickly and without explanation and recognition that the explanation has been understood. Objects or pictures can be useful in explaining any procedures. Also, any aids or appliances, such as the use of a beaker or specialised cutlery, must be discussed with the patient’s primary carer; this information should be available in the patient’s Health Passport/Health Action Plan.

From 1st August 2016 onwards, all organisations that provide NHS care and / or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

The link below provides access to the NHS England website if further information on accessible information is required.

http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/

5.4. Support to Make Decisions and Mental Capacity

PWLD/A must be supported to exercise their capacity to make decisions and to consent to care and treatment where the healthcare practitioner determines that they have the capacity to do so. The healthcare practitioner must assume that the person has capacity to make decisions.

The emphasis is on staff establishing the reasons why they consider that the person lacks the capacity to make each particular decision at the time it has to be made. This must be based on reasonable belief. In those circumstances where the healthcare practitioner determines that the person is unable to exercise full capacity to consent to care and treatment, every effort must be made to ensure that the person understands in simple terms the risks and benefits associated with that care and treatment.

Every effort must be made to help and support the person to maximise their potential to make their own decisions or, at least, to participate as fully as possible. Healthcare practitioners must consider how much information to convey to the person and how to make the most of the abilities that 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 simple language or through the use of pictures and photos.

Particular needs of people with learning disability and/or autism in relation to decision making and giving consent

People with learning disabilities and/or autism may have particular difficulties in relation to decision making and giving consent for some of the following reasons:

- Difficulty understanding relevant information, which is linked to the person's verbal and general cognitive skills (e.g. difficulties with attention, distractibility) and the methods used to convey information
- Difficulty retaining relevant information
- Difficulty appreciating the personal significance of information
- Difficulty with reasoning and use of information to arrive at a decision (e.g. concreteness, difficulties with abstracting and generalising)
- Lack of experience of decision making
- Tendency to acquiescence and suggestibility, and difficulties being assertive
- Emotional factors such as fear, anxiety, frustration
- Difficulties in expressing choices.

Some of these difficulties relate to the person's learning disability in that their cognitive function is limited in some areas. Others reflect the person's social and psychological experience (e.g. relative powerlessness) and represent "secondary handicaps". Support should be provided to maximise the person's ability to participate as fully as possible in decisions about their own life.

For further information on mental capacity and consent to treatment and the appropriate mental capacity assessment, best interests and consent forms, see the **Mental Capacity Act 2005** and the Mental Capacity Act Policy.

5.5. Information Sharing

All patients have a right to privacy and to control information about themselves. Where the person lacks capacity, this right must be balanced with the protection of their interests. Although carers/support workers will be involved in best interest's decisions there should not be widespread disclosure of personal health information without the person's valid consent and information should be shared on a need to know basis.

Information pertinent to any change in the person's support needs should be shared with learning disability care staff, but detailed clinical information should be treated sensitively and disclosed only when necessary and on a need to know basis.

It must not be assumed that the person's next of kin is the primary carer. Many PWLD/A live in registered care homes or in supported living environments; in these cases, the care provider is responsible for the health and well-being of the patient.

Care staff would therefore expect to be involved in best interest's discussions where the PWLD/A lacks capacity. Some PWLD/A have limited or intermittent contact with family members therefore care should be taken to ensure that information is disclosed appropriately and with the relevant people. PWLD/A should be consulted about who they wish to be included in discussions about clinical matters where possible.

Clinical information must be shared as appropriate by professional colleagues, i.e. therapist to therapist, etc. to ensure continuity of care.

5.6. Making Reasonable Adjustments

The Equality Act 2010 requires all health care providers by law to make reasonable adjustments to their services to ensure PWLD/A have equal access, care 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. Advice and guidance can be sought from the Safeguarding Matron.

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 or carer/s to stay all the time.
- Allow flexible visiting hours for carers/support workers.
- Allowing individuals to walk to theatre.
- Doing other investigations whilst individuals are under anaesthetic.
- Giving individuals a quiet place to wait away from the main waiting area.
- Offering diversions.
- Use of comforters.
- Having one to one nursing.
- Making information easier to understand.
- Hiring a bed or chair more suited to their individual needs.
- Using a side room.
- Allowing more time with meals/drinks etc.
- Reduce distracting noise if possible.
- Ensure lighting is not too bright or intrusive as this can be stressful for PWLD/A

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

5.7. Carer involvement

The term 'carer' is used to indicate anyone supporting the PWLD/A – this could be a family member, relative, support worker, or advocate. It should be recognised that the carer of a PWLD/A has considerable insight into the care of that person and are in a unique position in understanding their needs. They will also be able to help staff to identify ways to communicate most effectively with the patient.

The patient will benefit if care and treatment is delivered in partnership with the carer, but assumptions should not be made about the level of involvement that the carer is able to provide. Carer's should not be relied upon to provide extra support. However, they should be made welcome and be encouraged to continue to assist in providing care in partnership with the nursing and medical staff should they wish to do so. Carer's should also be encouraged to participate in the nursing assessment, planning care and discharge.

When a patient is being supported by a carer not directly employed by the Trust, staff must ensure that the carer:
- receives support in providing care
- has effective two-way communication
- is aware of what care and treatment has been delivered and by whom
- that care and additional support is evaluated and communicated to the carer
- is allowed a break at regular short intervals and allowed to use staff facilities
- Is offered drinks at regular intervals
- Can stay with the patient overnight if needed and suitable sleeping equipment is provided
- does not provide 24-hour care

5.8. Challenging Behaviour

Some PWLD/A may exhibit behaviour that others consider challenging. This often occurs in response to communication issues, sensory stimulation, attracting attention, avoiding demands, distress, pain, boredom or environmental factors such as noise or crowds.

This behaviour often results from the interaction between personal and environmental factors and includes aggression, self-injury, stereotypic behaviour, withdrawal and disruptive or destructive behaviour.

It is relatively common for people with a learning disability to develop behaviour that challenges, and more common for people with more severe disability. Prevalence rates are around 5–15% in educational, health or social care services for people with a learning disability. Rates are higher in teenagers and people in their early 20's and settings (for example, 30–40% in hospital settings).

People with a learning disability who also have communication difficulties, autism, sensory impairments, sensory processing difficulties and physical or mental health problems (including dementia) may be more likely to develop behaviour that challenges. In order to support the person, it is beneficial to speak to the patient's carer/support worker to find out what may precipitate any challenging behaviour to try and minimise potential triggers. It is also good practice to ask whether the carer/support worker has any written strategies for coping with the challenging behaviour of the person they are caring for and if a copy can be made available to be used as part of the nursing care plan.

It is useful to determine whether carers/support workers have any other methods of distraction that they follow with the patient they are caring for which may help staff to better manage any challenging behaviour. Staff could also find out if there are any activities that the patient particularly enjoys and try to incorporate these into the daily ward routine.

5.9. Partnership working

Multi-agency and multi-disciplinary partnership working is essential to ensuring positive health outcomes for PWLD/A. The WCFT will support the development of strong partnership working with colleagues from all Community Learning Disability teams. Working together with other health and social care providers such as GP's who frequently provide support and health education in the community, social care providers such as Social Workers and Home Care providers and family carers requires effective communication and information sharing which is paramount to safeguarding the individual and prevent harm.

Family carers and support workers must be included in planning for both admission and discharge to ensure all information is passed on effectively and avoids anything being missed.

The WCFT will actively seek the views of PWLD/A, their carers and local support groups to inform both policy development and the strategic development of services. The Safeguarding Matron is fully involved in networking with other acute Trusts to ensure best practice is shared, updated and informed about the regional and national learning disabilities and autism agendas.

6. Elective Admissions

When attending the Pre-Assessment Clinic and on admission, the PWLD/A or their family / carer / health facilitator will be asked for any copies of care plans and nursing assessments including the Health/Hospital Passport and personal Health Action Plan if the person has one. If they do not have a Health/Hospital Passport, this should be completed with them at pre-assessment or on admission. Copies of the Health Passport are available on the Safeguarding pages on the Trust intranet.

In pre-assessment (or on admission if no pre-assessment) the health care practitioner completing the assessment will need to discuss the specific needs of the person and may need to contact the person's family, carer, healthcare facilitator, Social Worker or Community Nurse to ensure a full assessment of need.

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
- behaviours which are challenging
- pain management
- transport needs
- special possessions to bring into hospital
- discharge arrangements

Where possible the PWLD/A and carer will be offered the opportunity to visit the ward and familiarise themselves with the hospital and staff caring for them prior to admission. The PWLD/A will also be offered the opportunity to ask further questions about the planned procedure. Consideration should be given to combine procedures wherever possible. During anaesthesia, there could be opportunities to undertake blood tests or other procedures to avoid any further distress to the patient.

The pre-assessment appointment (besides pre-ward visits) should be planned with as much time before admission as possible to ascertain information on the patient and the required care levels to disseminate to the admitting ward.

Provision should be made for a side room to lessen anxiety or distress and to give extra space, especially if the parent or carer is staying overnight to support the patient and to accommodate any extra equipment required. The ward staff will need to negotiate between relevant carers and hospital staff to review all aspects of support needed within the hospital environment.

Liaison between relevant disciplines e.g. Occupational Therapy, Speech and Language Therapy and Physiotherapy will be established as needed and if further support is required, this will be agreed e.g. joint working between community and hospital therapy staff. If joint working is agreed, clinical responsibility rests with hospital staff who will determine the appropriate care and treatment for the PWLD/A, with community Learning Disability clinicians providing a supportive/advisory role.

On admission, the patient’s Health Passport/Health Action Plan (where available) should be incorporated within the admissions procedure, with all relevant information, particularly that relating to specific support needs available and accessible to all ward staff. Also a LD risk assessment should be completed within 48 hours of admission.

When surgery is required, ward staff should liaise with the Theatre and Recovery Unit staff to ensure all relevant information is discussed in relation to specific support needs. Parents and carers should be offered the opportunity to accompany the patient to the anaesthetic room and attend the recovery unit when the patient wakes following any surgery/procedure to offer support and reassurance.

7. Patients admitted from a Residential Home/Supported Living Schemes

The residential care home staff should fully appraise hospital staff during the pre-assessment process of any specific requirements for their client. They are responsible for providing the Health Passport/Health Action Plan which provides details of the individuals support needs.

The care provider may be able to offer some level of practical support while the patient is in hospital. However, the Local Authority, who pay for home care provision, may not sanction this and frequently advise care providers to stop support whilst the person is in hospital care.

Funding for 1-1 care for people when in acute hospitals

Evidence shows that when PWLD/A need a 1-1 for social communication care or exhibit challenging behaviour they will require carers who know them well to be on the ward to support the nursing staff to be able to provide clinical nursing care. If the care provider is able to offer support any such arrangement may involve the potential for reimbursement to the care provider for the use of their staff member and this must be discussed immediately with the Ward Manager/Senior Nurse responsible when the patient is admitted.

8. Outpatients Appointments/Day Ward Attendance

Where possible the PWLD/A and/or the family/carer will be asked to bring in with them the person’s Health Passport and/or a Health Action Plan. Details of the person’s health care facilitator / social worker / community nurse should be checked and recorded.

When booking and preparing for clinic appointments or day surgery the following considerations should be made:

- **Time of appointment**: PWLD/A may find waiting difficult. It is advisable to arrange a first appointment or first on the surgery list.
- **Length of appointment**: PWLD/A will take longer to assimilate information and may take longer to examine. It is advisable to offer double appointment times.
- **Waiting to be seen**: Offer a quiet waiting area or clinic room if possible
- **Communication needs**: There may be the need to use other communication strategies or aids during the consultation such as easy read literature, images/pictures or ‘objects of reference’.
- **Consent**: A PWLD/A 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.
- **Carer**: The person may well require a carer to accompany them throughout an appointment and into the anaesthetic room and recovery room in Surgery.
- **Environment**: PWLD/A can become frightened by things they do not understand so it may be necessary to remove unnecessary equipment or instrumentation. Where available, single rooms or a suitably quiet waiting area should be offered to minimise anxiety levels and avoid risks to other patients’ safety if the person is likely to exhibit challenging behaviour.

Where PWLD/A present with phobias/extreme anxieties or challenging behaviour, consideration to the following areas are a necessity to meet their needs:

- sedation should be planned in advance as needed.
- where the person is likely to exhibit challenging behaviour, the relevant nursing/medical staff will liaise with the carer/s to fully assess risk and plan how they can jointly manage these situations. It should not be assumed that the carer/s will manage all situations independently.

In cases where the service user presents with distress, extreme anxiety or challenging behaviour in hospital settings follow up appointments should be avoided unless clinically essential.

9. Diagnostic Tests and Investigations

Tests and investigations can be very frightening to many PWLD/A so adjustments should be made to reduce anxiety and distress 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/signs or symbols.
- Not rushing the person.
- Arranging for the person and their carer to leave the clinic/department if a wait is envisaged and then contacting them when their appointment is ready.

An assessment should take place when booking a diagnostic test or investigation to ensure that similar considerations are given to those issues addressed in previous paragraph

In addition, staff should also consider:

- **Privacy and Dignity**: PWLD/A may be reluctant to undress and will need help and persuasion to do so.
- **Comforters**: PWLD/A 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 unusual or challenging behaviour.
- **Directions**: PWLD/A 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 PWLD/A during the test or investigation.

10. Discharge from Hospital

In addition to the procedures laid down in the Discharge Policy supplementary actions may
need to be taken. Planning for discharge should commence as soon as a PWLD/A is admitted. On admission, the patient and/or his/her carer will be advised of a provisional date for discharge. This date will be reviewed daily and may involve a number of staff from the hospital team. The nurse in charge will liaise with the individual and/or his/her carer about safe discharge to home from hospital.

The Safeguarding Matron should be informed of any admission of a PWLD/A and dialogue established with the Discharge Planning Team. Any factors which may prevent discharge back to the patient’s home should be flagged up to the Discharge Planning Team and the Safeguarding Matron as soon as possible. It is possible that the patient will require additional after care on discharge.

PWLD/A 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.

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, Social Worker, Specialist Speech and Language Therapist, Occupational Therapist, Physiotherapist etc. They can support the gathering of accurate information and identification of potential risks to safe discharge.

A PWLD/A may live with a partner or family member who also has a learning disability and//or autism and in these circumstances detailed planning of the discharge and support will be required to ensure a safe discharge.

Careful consideration must be given to providing advice for after-care and treatment. A PWLD/A 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.

The practitioner discharging the patient should provide a discharge sheet with accessible ‘easy read’ information, covering diagnosis, treatment, when to return for follow-up appointments, any possible side effects of medication and details of someone on the ward to contact if necessary.

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, boxes with larger print and additional accessible information leaflet etc. Clinicians must check with residential care homes if documentation is required to allow care staff to administer any new medication.

A copy of the Discharge Summary should be given to the primary care provider and advice should be given regarding any changes in health need, treatment, medication and follow-up.

It is essential that all follow-up appointments are discussed with the primary carer to ensure a clear understanding of who will be responsible for the patient's care once they have left hospital.

The primary carer must be involved in discussions relating to discharge arrangements. It is crucial that the primary carer attends any multidisciplinary discharge meeting to ensure effective co-ordination.

Prior to discharge, a multidisciplinary meeting of all key parties (including family members as appropriate) involved in the care of the patient should be considered to plan the discharge, especially where there has been a significant change in the patient's health needs or if the patient has severe learning disabilities, complex health care needs or is considered vulnerable.

The community learning disability practitioners involved may have to co-ordinate training for carers to manage the changing health needs and/or review the need for temporary respite care or a permanent alternative placement. Community learning disability practitioners may also need to provide details of specialised equipment that is used regularly, such as a wheelchair, feeding equipment, splints etc.

If the patient has no representative, family member or friend, it may be appropriate to request the involvement of an Independent Mental Capacity Advocate (IMCA). [See the Mental Capacity Act 2005 and Mental Capacity Act Policy.

11. STOMP (Stopping over medication of people with a learning disability, autism or both)

In April 2018, NHS England and partners launched STOMP pledge for health care providers. The aim of STOMP is to:

- encourage people to have regular check-ups about their medicines
- make sure doctors and other health professionals involve people, families and support staff in decisions about medicines
- Inform everyone about non-drug therapies and practical ways of supporting people so they are less likely to need as much medicine, if any.

People with a learning disability, autism or both are more likely to be given these medicines than other people. These medicines are right for some people. They can help people stay safe and well. Sometimes there are other ways of helping people, so they need less medicine or none.

There is an easy read leaflet about the project and supporting people who take psychotropic medicine. NHS England wrote it with MiXit, a theatre company for people with and without a learning disability, and with help from other people and families.

It can be accessed via this hyperlink:

https://www.england.nhs.uk/wp-content/uploads/2018/02/stomp-easy-read-leaflet.pdf

The Trust is currently working in partnership with the Acute Liaison Learning Disability Group to develop an action plan for STOMP which will be submitted to NHS England and displayed on Trust Intranet to show the Trust commitment to stopping over medication of people with a learning disability, autism or both.

12. Mortality Review and the LeDeR Programme

The report from the Confidential Inquiry recommended that when someone with learning disabilities dies, we should check what happened (CIPOLD) as research has found that men with a learning disability die on average 13 years sooner, and women with learning disability 20 years sooner, compared to those without learning disabilities.

The LeDeR Programme has been set up to contribute to improvements in the quality of health and social care for people with learning disabilities in England. It will do so by supporting local areas to carry out local reviews of deaths of people with learning disabilities. Through an agreed local review process, it aims to firmly embed the responsibility for conducting the reviews and implementing any recommendations and plans of action, into the hands of regional and local services.

The Learning from Deaths guidance states that deaths of people with learning disabilities that occur whilst the person is in hospital should be notified to the LeDeR programme. The deaths should be reviewed using the LeDeR methodology, and an anonymised copy of the completed report sent back to the notifying Trust upon completion of the review. (Appendix 3 contains the notification of death flowchart to help understand how each review process works in parallel with each other.)

The Trust has a current Mortality Review policy in place in relation to the Learning from Deaths guidance. This policy can be accessed by the Trust intranet.

The nominated Trust lead for telling the LeDeR programme that someone with learning disability has died is the Matron for Safeguarding.

Notification of a death

Reporting a death of a person with learning disabilities can be done in a number of ways and by anyone:

- via [redacted] directly to a member of the central LeDeR programme team, or
- via the Programme's secure web-based portal, which can be accessed through the LeDeR website or via the following link: http://www.bristol.ac.uk/sps/leder/notify-a-death/

The person reporting the death is asked to provide as much of the core information required to notify a death as possible. The information provided is checked by the

LeDeR team to ensure that the death meets the inclusion criteria for the LeDeR programme. Once confirmed the death is allocated to a reviewer under the guidance of the local area contact.

For further information about the LeDeR programme, please click the following link: http://www.bristol.ac.uk/sps/leder/about/

13. End of Life Guidance

It is important to view all people holistically when providing end of life care. People with a learning disability, like other members of society, will have a range of characteristics that may inform their needs and expectations in relation to end of life care. For example, expectations about end of life care may be shaped by someone's ethnicity, faith, values and/or other beliefs.

It is important not to make assumptions about the care the person needs because of their learning disability diagnosis. Rather the aim should be to effectively engage with individuals, their families and carers to ascertain their individual needs, expectations and wishes.

A 'top tips' guidance has been developed by NHS England in association with the Palliative Care for People with Learning Disabilities (PCPLD) Network. The development process involved consultation with Public Health England and a range of commissioners, providers and professionals working within palliative and end of life care and learning disability settings.

People with lived experience have also helped us to develop the guide. Please access the guide by clicking the link below: https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

'The Leadership Alliance for the Care of Dying People' (2014) produced a glossary of terms that includes helpful definitions of palliative and end of life care. You can find the full glossary in 'One chance to get it right', published on the gov.uk website. Please click link below:

https://www.gov.uk/government/publications/ liverpool-care-pathway-review-response-to-recommendations)

The Trust has a current End of Life Strategy which can be accessed via the Trust intranet.

14. Transition into Adult Services

The transition from children's services to adults' services is often very challenging for young people with a learning disability and their families: it combines a change of services and professionals at the very time when they are also negotiating wider changes to their life, for example in their educational circumstances.

This is likely to be necessary for young people with complex needs who are going to continue to need significant levels of support from adult services. The complexity of their needs will mean that meticulous planning and a gradual transition to new services will be required. It should also include any education and /or health care plan which may hold useful information about their needs.

The assessment is the starting point and could be requested years in advance of their 18th birthday to allow sufficient time for this planning and transition to take place. In England, when the transition between children's and adults' services takes place, a local authority must continue to provide the individual with any children's services they were receiving throughout the assessment process. This will continue until adult care and support is in place to take over – or until it is clear after the assessment that adult care and support does not need to be provided.

These changes will mean there is no "cliff-edge" where someone reaching the age of 18 who is already receiving support will suddenly find themselves without the care and support they need at the point of becoming an adult.

Please click on following link for further information from the Transition Information network http://councilfordisabledchildren.org.uk/transition-information-network/information-and-support/health

15. Training

It is recognised that staff may require additional skills/knowledge to enable them to meet the requirements of the policy. This will be addressed via the existing internal Training and Development programme, which includes awareness sessions for caring for those with learning disabilities.

Where additional expertise is required, contact should be made with the patient's local LD team. If necessary staff can arrange for the Learning Disability facilitators from CCGs/Mersey Care NHS Trust to come into the Trust to provide guidance.

Learning Disabilities Core Skills Education and Training Framework

The framework is particularly relevant to employers, their employees and to educational organisations which train students who will be employed in the health, social care and other sectors.

Use of the framework will support organisations to:

- standardise the interpretation of learning disabilities education and training
- guide the focus and aims of learning disabilities education and training delivery
- ensure the educational relevance of learning disabilities training
- improve the quality and consistency of education and training provision.

The framework also supports the assessment of competence, training needs analysis and provision of minimum standards of performance within performance management systems (e.g. as part of supervision or appraisal).

http://www.skillsforhealth.org.uk/images/resource-section/projects/learning-disabilities/Learning-Disabilities-CSTF.pdf

16. Monitoring

The policy will be reviewed every three years in accordance with the Trust policy review process. Unless there is a change in Department of Health legislation or policy which requires the Trust to review learning disability practice the policy will be updated sooner.

Audit

The policy will be audited for compliance of the following points:

- Identification of LD /ASD status at referral triage (check documentation in written referral and/or recorded in electronic triage form) record as additional needs on referral documentation.
- Client Risk Identifier alert code applied for LD/ASD status coded on Patient Administration System (PAS) and on EP2
- Appropriate completion of patient alert record.
- Appropriate completion of LD risk assessment
- Evidence of reasonable adjustments
- Recorded use of patient’s hospital support plan or health action plan (“hospital passport”).
- Compliance with process.

17. References

- DoH (2013) Government response to the Confidential Inquiry into premature deaths of people with learning disabilities.
- DoH (2013) Transforming care: A national response to Winterbourne View Hospital
- Public Health England Improving Health and Lives: Learning Disabilities Observatory (2011) Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers. Evidence in practice report no.3.
- NHS England, Building the right support, October 2015
- 'Winterbourne View - Time for Change' Report (2014)
- Care services for people with learning disabilities and challenging behaviour (March 2015)
- DH (2009) The Autism Act 2009. London: The Stationery Office.
- DH (2009) Valuing People Now: A New Three-Year Strategy for people with learning 79disabilities: “Making it happen for everyone”. London: Stationary Office.
- DH (2010) The Equality Act. London: Department of Health.
- DH (2010) Fulfilling and rewarding lives: the strategy for adults with autism in England. London: Department of Health.
- Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriot, A., Russ, L. (2013) Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report. Bristol: Norah Fry Research Centre.
- MENCAP (2004) Treat Me Right! Better healthcare for people with a learning disability. London: MENCAP.
- MENCAP (2007) Death by Indifference. Following up the Treat me right! report. London: MENCAP.
- MENCAP (2012) Death by indifference: 74 deaths and counting - A progress report 5 years on. London: MENCAP.
- Michael, J. (2008) Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities. London: The Stationery Office.
- NICE (2014) Autism Quality Standard. NICE clinical guideline. London: National Institute for Health and Care Excellence.
- Parliamentary and Health Service Ombudsman (2009) Six Lives: the provision of public services to people with learning disabilities. London: The Stationery Office.
- Accessible Information Standard https://www.england.nhs.uk/ourwork/accessibleinfo/

17.1. Supporting policies/documents;

- Safeguarding Adults Policy
- Safeguarding Children Policy
- Consent Policy
- Deprivation of Liberty (DoLS) Policy
- Mental Capacity Act (MCA) Policy
- Restrictive Interventions Policy
- Chaperone Policy
- Special Observations Policy

Appendix 1 - Questions to help identify an individual’s additional needs

The following questions will be asked when:

- Booking a patient’s first appointment,
- Arranging an emergency or elective admission,
- Arranging investigations
- Follow-up appointments.

The individual will have the PAS Client Risk Identifier alert code LD flag, and telephone contact might either be with the individual or their carers/guardian.

Communication needs to be clear and not rushed. It is recognised that young people and their carer’s, in the transition for paediatric services experience additional stress and worry, due to their awareness of the young person’s additional needs and moving into a new hospital environment.

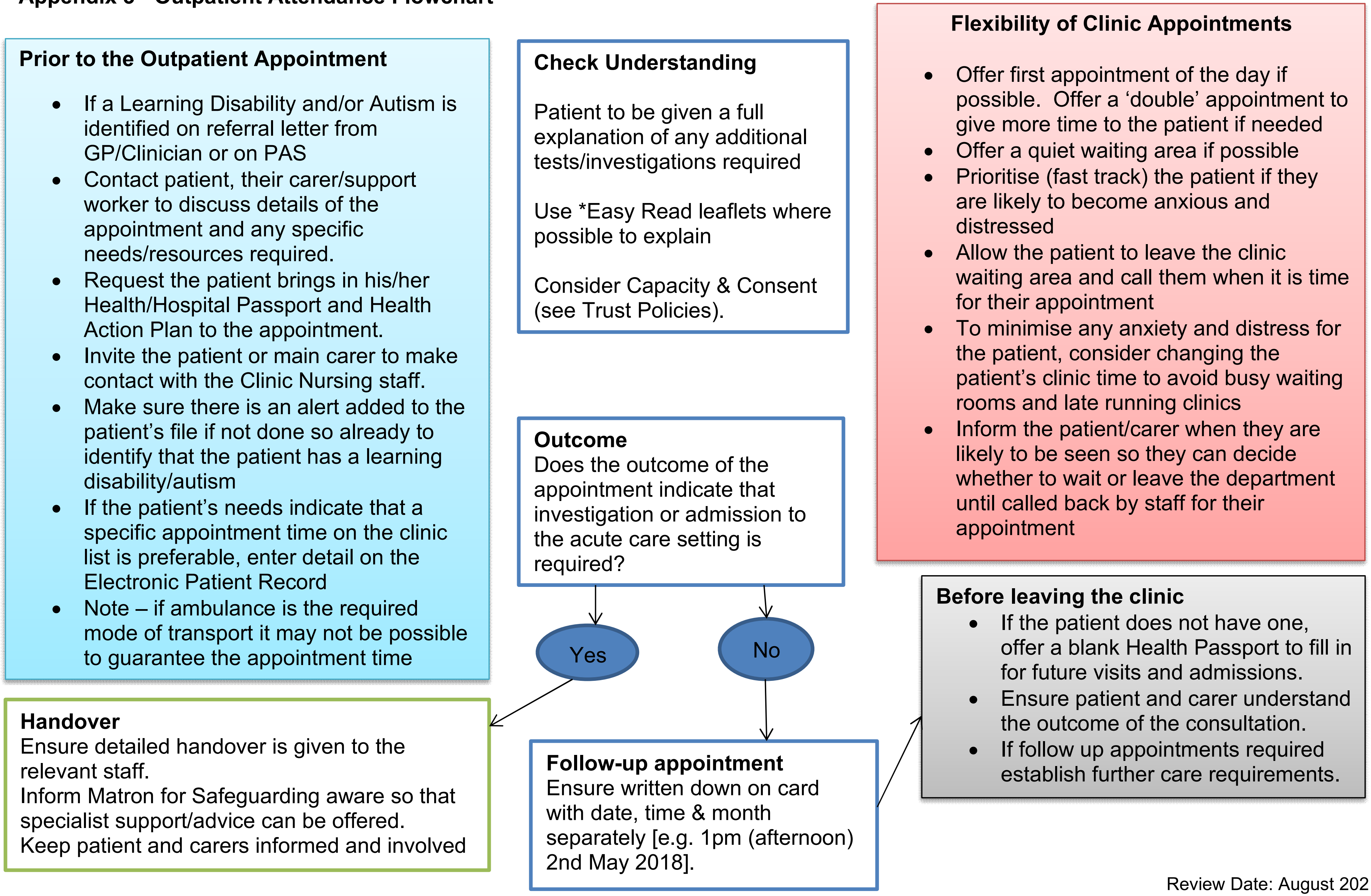
Questions to help identify an individual’s additional needs (reasonable adjustments)
Question 1: Does the patient have any additional needs which might affect their ability to attend an outpatient appointment (investigation, ward admission)? Such as; ➢ unable to tolerate crowded places, ➢ unable to tolerate noisy environments, or ➢ become distressed by unfamiliar routine or individuals ➢ Difficulty with understanding and communicating?
Response
Question 2: Is the patient likely to present medically challenging behaviours? (For example - self-harm, refusing tests etc.?) Is the patient likely to present medically challenging behaviours that are harmful to others including: other patients, property, staff or visitors.
Response

Question 3: Can the patient maintain their own safety within the outpatient environment e.g. call for help, orientate themselves, are they liable to walk off, epilepsy?
Response
Question 4: Does the patient experience problems when attending new places or meeting new people? If yes, please specify
Response
Question 5: Do the patients currently use or require specialist equipment?
Response

Appendix 2 - Planned Admission Process

	Please offer the patient a side room if available so that patient carer can stay with the patient.
LD LEARNING DISABILITY **ASD** AUTISM SPECTRUM DISORDER	LD AND ASD alert to be placed on patient record on PAS and EP2 (seek patient consent where appropriate)
 This is my Hospital Passport	Please ask for the patients' Health or Autism passport or complete one if patient does not have one. Access to the Trust Health Passport and Autism passport is on the safeguarding page of the intranet. The completed passport is stored at the end of the patient's bed whilst the patient is in the hospital.
	Complete full nursing/risk assessments on day of admission on EP2. Please ensure that you complete the Learning Disability Rapid risk assessment for patients with a learning disability within 48 hours of admission. This document can be accessed on EP2 under the name of *`LD Risk Assessment `*

Appendix 3 - Outpatient Attendance Flowchart



Prior to the Outpatient Appointment

- If a Learning Disability and/or Autism is identified on referral letter from GP/Clinician or on PAS
- Contact patient, their carer/support worker to discuss details of the appointment and any specific needs/resources required.
- Request the patient brings in his/her Health/Hospital Passport and Health Action Plan to the appointment.
- Invite the patient or main carer to make contact with the Clinic Nursing staff.
- Make sure there is an alert added to the patient's file if not done so already to identify that the patient has a learning disability/autism
- If the patient's needs indicate that a specific appointment time on the clinic list is preferable, enter detail on the Electronic Patient Record
- Note – if ambulance is the required mode of transport it may not be possible to guarantee the appointment time

Check Understanding

Patient to be given a full explanation of any additional tests/investigations required

Use *Easy Read leaflets where possible to explain

Consider Capacity & Consent (see Trust Policies).

Flexibility of Clinic Appointments

- Offer first appointment of the day if possible. Offer a 'double' appointment to give more time to the patient if needed
- Offer a quiet waiting area if possible
- Prioritise (fast track) the patient if they are likely to become anxious and distressed
- Allow the patient to leave the clinic waiting area and call them when it is time for their appointment
- To minimise any anxiety and distress for the patient, consider changing the patient's clinic time to avoid busy waiting rooms and late running clinics
- Inform the patient/carer when they are likely to be seen so they can decide whether to wait or leave the department until called back by staff for their appointment

Outcome

Does the outcome of the appointment indicate that investigation or admission to the acute care setting is required?

Yes

No

Handover

Ensure detailed handover is given to the relevant staff.
Inform Matron for Safeguarding aware so that specialist support/advice can be offered.
Keep patient and carers informed and involved

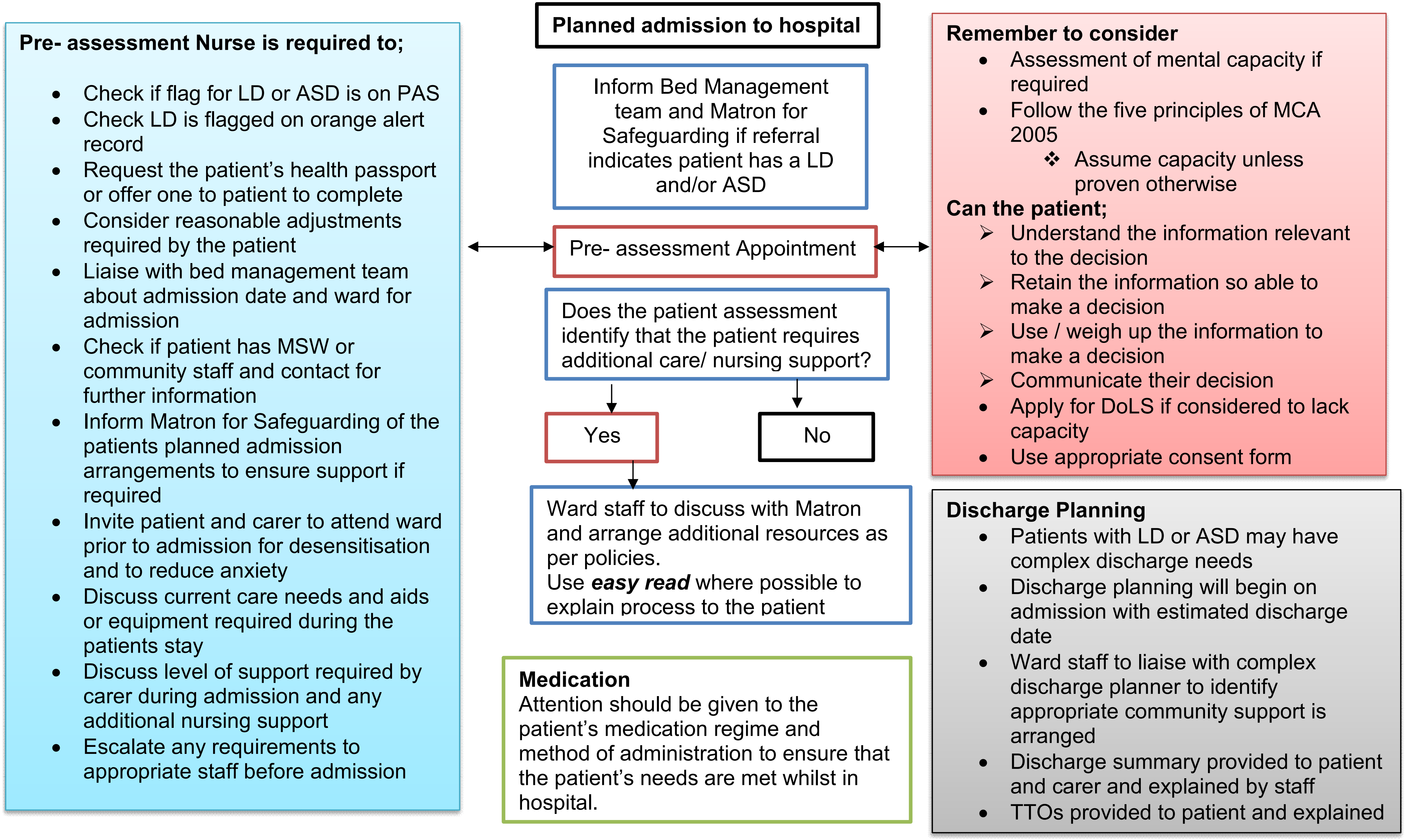
Follow-up appointment

Ensure written down on card with date, time & month separately [e.g. 1pm (afternoon) 2nd May 2018].

Before leaving the clinic

- If the patient does not have one, offer a blank Health Passport to fill in for future visits and admissions.
- Ensure patient and carer understand the outcome of the consultation.
- If follow up appointments required establish further care requirements.

Appendix 4 - Planned Admission Process



Planned admission to hospital

Inform Bed Management team and Matron for Safeguarding if referral indicates patient has a LD and/or ASD

Pre- assessment Appointment

Does the patient assessment identify that the patient requires additional care/ nursing support?

Yes

No

Ward staff to discuss with Matron and arrange additional resources as per policies.
Use ***easy read*** where possible to explain process to the patient

Pre- assessment Nurse is required to;

- Check if flag for LD or ASD is on PAS
- Check LD is flagged on orange alert record
- Request the patient’s health passport or offer one to patient to complete
- Consider reasonable adjustments required by the patient
- Liaise with bed management team about admission date and ward for admission
- Check if patient has MSW or community staff and contact for further information
- Inform Matron for Safeguarding of the patients planned admission arrangements to ensure support if required
- Invite patient and carer to attend ward prior to admission for desensitisation and to reduce anxiety
- Discuss current care needs and aids or equipment required during the patients stay
- Discuss level of support required by carer during admission and any additional nursing support
- Escalate any requirements to appropriate staff before admission

Remember to consider

- Assessment of mental capacity if required
- Follow the five principles of MCA 2005
    - ❖ Assume capacity unless proven otherwise

Can the patient;

- ➢ Understand the information relevant to the decision
- ➢ Retain the information so able to make a decision
- ➢ Use / weigh up the information to make a decision
- ➢ Communicate their decision
- Apply for DoLS if considered to lack capacity
- Use appropriate consent form

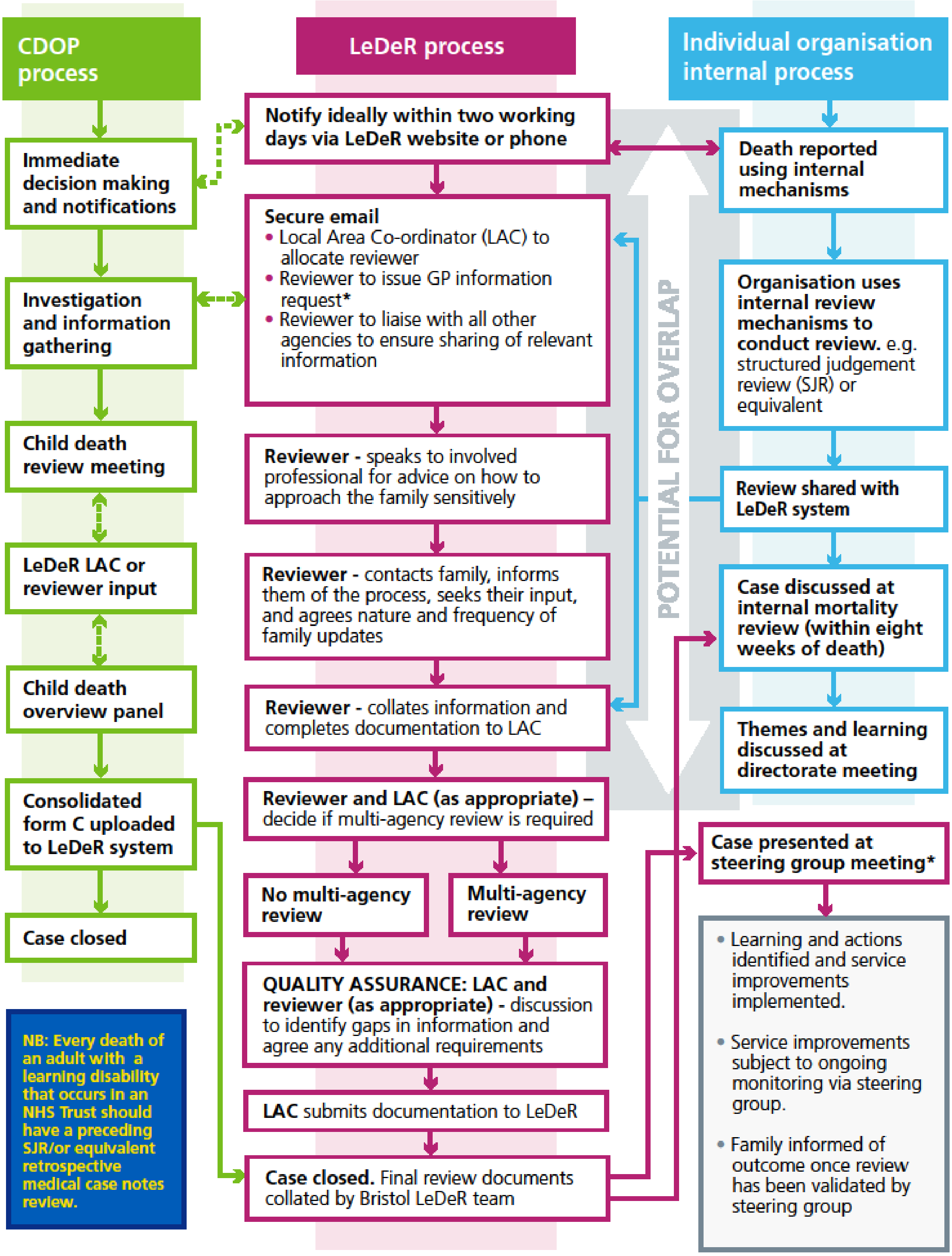
Medication
Attention should be given to the patient’s medication regime and method of administration to ensure that the patient’s needs are met whilst in hospital.

Discharge Planning

- Patients with LD or ASD may have complex discharge needs
- Discharge planning will begin on admission with estimated discharge date
- Ward staff to liaise with complex discharge planner to identify appropriate community support is arranged
- Discharge summary provided to patient and carer and explained by staff
- TTOs provided to patient and explained

Appendix 5 - Notification of Death of an Adult/Child with Learning Disability Flowchart

Notification and review of a death of an adult (18+) or child (age 4+) with a learning disability



CDOP process

- **Immediate decision making and notifications**
- **Investigation and information gathering**
- **Child death review meeting**
- **LeDeR LAC or reviewer input**
- **Child death overview panel**
- **Consolidated form C uploaded to LeDeR system**
- **Case closed**

NB: Every death of an adult with a learning disability that occurs in an NHS Trust should have a preceding SJR/or equivalent retrospective medical case notes review.

LeDeR process

- **Notify ideally within two working days via LeDeR website or phone**
- **Secure email**
  - Local Area Co-ordinator (LAC) to allocate reviewer
  - Reviewer to issue GP information request*
  - Reviewer to liaise with all other agencies to ensure sharing of relevant information
- **Reviewer -** speaks to involved professional for advice on how to approach the family sensitively
- **Reviewer -** contacts family, informs them of the process, seeks their input, and agrees nature and frequency of family updates
- **Reviewer -** collates information and completes documentation to LAC
- **Reviewer and LAC (as appropriate) –** decide if multi-agency review is required
- **No multi-agency review**
- **Multi-agency review**
- **QUALITY ASSURANCE: LAC and reviewer (as appropriate) -** discussion to identify gaps in information and agree any additional requirements
- **LAC** submits documentation to LeDeR
- **Case closed.** Final review documents collated by Bristol LeDeR team

POTENTIAL FOR OVERLAP

Individual organisation internal process

- **Death reported using internal mechanisms**
- **Organisation uses internal review mechanisms to conduct review.** e.g. structured judgement review (SJR) or equivalent
- **Review shared with LeDeR system**
- **Case discussed at internal mortality review (within eight weeks of death)**
- **Themes and learning discussed at directorate meeting**
- **Case presented at steering group meeting***
  - Learning and actions identified and service improvements implemented.
  - Service improvements subject to ongoing monitoring via steering group.
  - Family informed of outcome once review has been validated by steering group

Please note: Parts of a process marked with an * may be subject to regional variation. If in doubt consult your regional co-ordinator

Appendix 6 - Acute Liaison Hospital Network/Community Team Contact Details

Hospital	Team Contact
Walton Centre NHS Foundation Trust Lower Lane Liverpool L9 7LJ	[redacted]
Royal Liverpool & Broadgreen University Hospital Prescott Street Liverpool L7 8XP	[redacted]
Aintree University Hospital Longmoor Lane Liverpool L9 7AL	[redacted]

Hospital	Team Contact
Liverpool Heart and Chest Hospital NHS Trust Thomas Drive Liverpool L14 3PE	[redacted]
Women's Hospital Crown Street Liverpool L8 7SS	[redacted]
Alder Hey Children's Hospital NHS Trust East Prescot Rd Liverpool L14 5AB	[redacted]
St Helens and Whiston Hospital NHS Trust Whiston Hospital Warrington Rd Rainhill Prescot L35 5DR	[redacted]
Southport and Ormskirk Hospital Trust Town Ln Kew Southport PR8 6PN [redacted]	[redacted]

Hospital	Team Contact
Wirral University Teaching Hospital NHS Trust Arrowe Park Rd, Upton, Birkenhead, Wirral CH49 5PE	[redacted]
Clatterbridge Cancer Centre Clatterbridge Road Bebington Wirral CH63 4JY	[redacted]

Community Learning Disabilities Team

Cheshire and Merseyside

CCG Area	Contact	Manager	Health Facilitator
North West Boroughs Healthcare NHS Foundation Trust Knowsley	Address: 23 Cumber Lane Willis House Whiston [redacted]	[redacted]	[redacted]
North West Boroughs Healthcare NHS Foundation Trust St Helens	23 Cumber Lane Willis House Whiston [redacted]	[redacted]	
Warrington	Warrington Learning Disabilities 2nd Floor Hollins Park Hospital Hollins Lane Winwick Warrington Cheshire WA2 8WA **Tel:** [redacted]	[redacted]	[redacted]
Halton	Community Learning Disability Nurse Oak Meadow Community Support Centre Peel house Lane Widnes WA8 6TJ **Tel:** [redacted]	[redacted]	No current health facilitator

CCG Area	Contact	Manager	Health Facilitator
Liverpool	Mersey Care NHS Foundation Trust Community Hub Local Services Division Learning Disabilities Service Norris Green Falklands Approach Liverpool L11 5BS **Tel:** [redacted]	[redacted]	[redacted] [redacted]
Sefton	Sefton Community Learning Disability Team Hesketh Centre 51-55 Albert Road Southport PR9 0LT [redacted]	[redacted]	[redacted]
West Cheshire and Vale Royal	Address Wyvern House The Drumber Winsford CW7 1AH	[redacted]	[redacted] [redacted]
East & South Cheshire	Rosemount Lodge Rosemount Site Lea Bank Close Macclesfield SK11 8HE Telephone number: [redacted]	[redacted]	[redacted] [redacted]

CCG Area	Contact	Manager	Health Facilitator
Wirral	Ashton House, 26 Village Road, Oxton Wirral CH43 5SR Telephone number [redacted]	[redacted]	[redacted]
Cheshire & Wirral LD CAMHS Service	East/South (Including Vale Royal) Elm House Lea Bank Road Macclesfield SK11 8QA	[redacted]	[redacted]
Cheshire & Wirral LD CAMHS Service	West Cheshire Team 4th Floor North Wing 4 Civic Way Ellesmere Port CH65 0BE	[redacted]	[redacted]

Appendix 7 - Equality Impact Assessment (EIA) Form

The Walton Centre NHS
NHS Foundation Trust

This section must be completed at the development stage i.e. before ratification or approval. For further support please refer to the EIA Guidance on the Equality and Diversity section of the Intranet.

Part 1

1. Person(s) Responsible for Assessment: [redacted]

2. Contact Number: [redacted]

3. Department(s): Corporate

4. Date of Assessment: 07/08/2018

5. Name of the policy/procedure being assessed: Learning Disability

6. Is the policy new or existing? Existing√

7. Who will be affected by the policy (*please tick all that apply*)? Staff √ Patients √

8. How will these groups/key stakeholders be consulted with?
Staff feedback based on policy implementation and operational performance will be incorporated.

9. What is the main purpose of the policy?

This policy sets out the standards of care the WCFT wishes to provide to people with a learning disability and/or autism that access our services

10. What are the benefits of the policy and how will these be measured?

Everyone within WCFT has a responsibility for and is committed to ensuring all people with a learning disability and/or autism (PWLD/A) receive the correct care and support required regardless of any associated problem relating to their LD and/or Autism.
This will be measured through audit.

11. Is the policy associated with any other policies, procedures, guidelines, projects or services? *If yes, please give brief details*

Safeguarding Adults Policy, Safeguarding Children Policy, Consent Policy, Deprivation of Liberty (DoLS) Policy, Mental Capacity Act (MCA) Policy, Restrictive Interventions Policy, Chaperone Policy and Special Observations Policy

12. What is the potential for discrimination or disproportionate treatment of any of the protected characteristics?

None

Protected Characteristic	**Positive Impact *(benefit)***	**Negative *(disadvantage or potential disadvantage)***	**No Impact**	**Reasons to support your decision and evidence sought**	**Mitigation/adjustments already put in place**
Age	√			All patients with LD will be treated the same regardless of age	Accessible information leaflets are available. Staff communication is encouraged to support patients with LD.
Sex	√			All identified patients with LD will be treated the same Irrespective of their gender.	
Race	√			All identified patients with LD will be treated the same Irrespective of their race and ethnicity.	The Trust operates within the requirements of the Race Equality Act 2010. Language may be a barrier – interpreters are made available when required.
Religion or Belief	√			All patients with LD will be treated the same irrespective of their belief system	There is access to the multi faith chaplaincy team who offer advice, & support for Pts, relatives, carers & staff
Disability	√			It is acknowledged that some patients with LD may also live with other disabilities including mental health & sensory impairments	Information and advice is accessible, up to date, and free from jargon. All areas have disabled access re: wheelchairs; lifts; toilets. Any issues regarding a disability would be taken into consideration at time of patient assessment and all support tailored to meet individual need.
Sexual Orientation	√			All patients with LD will be treated the same irrespective of their sexual orientation.	Trust staff is bound to comply with equalities legislation. Staff training is available for equality & diversity. All complaints would be fully investigated and responded to.
Pregnancy/maternity	√				
Gender Reassignment	√			All patients with LD will be treated the same irrespective of their gender.	Trust staff are bound to comply with equalities legislation. Staff training is available for equality & diversity. All

					complaints would be fully investigated and responded to.
Marriage & Civil Partnership	√				
Other	√				

If you have identified no negative impact for all please explain how you reached that decision and provide reference to any evidence (e.g. reviews undertaken, surveys, feedback, patient data etc.)

13. Does the policy raise any issues in relation to Human Rights as set out in the Human Rights Act 1998? *See Guidance for more details (NB if an absolute right is removed or affected the policy will need to be changed. If a limited or qualified right is removed or affected the decision needs to be proportional and legal).*
No

If you have identified negative impact for any of the above characteristics, and have not been able to identify any mitigation, you MUST complete Part 2, please see the full EIA document on the Equality and Diversity section of the Intranet and speak to [redacted]

Action	**Lead**	**Timescales**	**Review Date**

Declaration

I am satisfied this document/activity has been satisfactorily equality impact assessed and the outcome is:

No major change needed – EIA has not identified any potential for discrimination/adverse impact, or where it has this can be mitigated & all opportunities to promote equality have been taken ☒

Adjust the policy – EIA has identified a need amend the policy in order to remove barriers or to better promote equality
You must ensure the policy has been amended before it can be ratified. ☐

Adverse impact but continue with policy – EIA has identified an adverse impact but it is felt the policy cannot be amended.
You must complete Part 2 of the EIA before this policy can be ratified. ☐

Stop and remove the policy – EIA has shown actual or potential unlawful discrimination and the policy has been removed ☐

Name: Date:

Signed: or/Sent from work email account

Appendix 8 - Policy approval checklist

The Learning Disability Policy is presented to Patient Safety Group for Approval.

In order for this policy to be approved, the reviewing group must confirm in table 1 below that the following criteria is included within the policy. Any policy which does not meet these criterion should not be submitted to an approving group/committee, the policy author must be asked to make the necessary changes prior to resubmission.

Policy review stage

Table 1

The reviewing group should ensure the following has been undertaken:	**Approved?**
The author has consulted relevant people as necessary including relevant service users and stakeholders.	√
The objectives and reasons for developing the documents are clearly stated in the minutes and have been considered by the reviewing group.	√
Duties and responsibilities are clearly defined and can be fulfilled within the relevant divisions and teams.	√
The policy fits within the wider organisational context and does not duplicate other documents.	√
An Equality Impact Assessment has been completed and approved by the HR Team.	√
A Training Needs Analysis has been undertaken (as applicable) and T&D have been consulted and support the implementation	√
The document clearly details how compliance will be monitored, by who and how often.	√
The timescale for reviewing the policy has been set and are realistic.	√
The reviewing group has signed off that the policy has met the requirements above.	√

Reviewing group chairs name: [redacted]	**Date: 09/08/2018**

Policy approval stage

☐ √ **The approving committee/group approves this policy.**

☐ **The approving committee/group does not approve the policy.**

Actions to be taken by the policy author:

Approving committee/group chairs name: [redacted]	**Date: 09/08/2018**

Appendix 9 - Version Control

Version	Section/Para/ Appendix	Version/description of amendments	Date	Author/Amended by
2.0		Complete Revision of Policy	09/08/18	[redacted]

Translation Service

This information can be translated on request or if preferred an interpreter can be arranged. For additional information regarding these services please contact The Walton centre on [redacted]

Gellir gofyn am gael cyfieithiad o'r deunydd hwn neu gellir trefnu cyfieithydd ar y pryd os yw hynny'n well gennych. I wybod rhagor am y gwasanaethau hyn cysylltwch â chanolfan Walton ar [redacted]

هذه المعلومات يمكن أن تُتَرْجَم عند الطّلب أو إذا فضّل المترجم يمكن أن يُرَتَّب للمعلومة الإضافيّة بخصوص هذه الخدمات من فضلك اتّصل بالمركز ولتون على [redacted]

ئەم زانیاریە دەکرێت وەربگێڕدرێت کاتێك کە داوابکرێت یان ئەگەر بەباش زاندرا دەکرێت
وەرگێڕێك ئامادە بکرێت (ڕێك بخرێت) ، بۆ زانیاری زیاتر دەربارەی ئەم خزمەتگوزاریانە تکایە
پەیوەندی بکە بە Walton Centre بە ژمارە تەلەفۆنی [redacted]

一经要求，可对此信息进行翻译，或者如果愿意的话，可以安排口译员。如需这些服务的额外信息，请联络Walton中心，电话是: [redacted]