EXECUTIVE SUMMARY

This policy has been developed to ensure that all staff are aware of, and follow, best practice in the care and support of patients with a Learning Disability and/or Autism. The Michael Report (2008) ‘Healthcare for All’ and the Ombudsman report ‘Six Lives’ (2009) made recommendations on the care of people with learning disabilities and/or autism and this policy has been developed to aid compliance with the recommendations put forward within these reports, the Autism Act (2009) and the standards set in the NICE Guideline for Autism (2014).
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SECTION 1 – INTRODUCTION

1.1 Policy Statement and Rationale

The Trust is committed to delivering care to patients that meets their individual needs and recognises that some patients 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. The West Suffolk NHS Foundation Trust (WSFT) 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 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.


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.

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

1.2 Key Principles

Everyone within WSFT has 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.

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 WSFT recognises these issues and is committed to ‘getting it right’ when meeting the needs of PWLD/A.

1.3 Background Information

The Equality Act 2010 makes it unlawful for service providers to treat disabled people less favourably for a reason relating to their disability. Equality for people with disabilities may require the organisation to make reasonable adjustments to its service to accommodate specific or additional support needs of those with disabilities.
1.4 Definitions

Learning Disability

Learning Disabilities affect approximately 1.5 million people in the UK and are common lifelong conditions which are neither illness nor disease. The term is used in relation to individuals who have the following 3 core characteristics:

- A significant impairment of intelligence, IQ below 70
- A significant impairment of adaptive and/or social functioning (ability to cope on a day-to-day basis with the demands of his/her environment and the expectations of age and culture)
- Age of onset before adulthood (18 years of age)

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.

PWLD/A may present as having:

- difficulties communicating and expressing needs and choices;
- difficulty understanding their diagnosis, treatment options or services available to them;
- difficulty understanding the consequences their decisions can have on their health status;
- difficulties in adapting to a hospital environment and the expectations of hospital staff.

The amount of everyday support a person with a learning disability needs will depend mostly on the severity of the disability. It is important to treat each person as an individual, with specific strengths and abilities as well as needs, and a broad and detailed assessment may be needed.

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 offer the best practice advice on the person centred care of people with autism. It highlights that support and care ‘should take into account 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.

**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 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, often known as the ‘Triad of impairments’:

- **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.

**SECTION 2 - ROLES AND RESPONSIBILITIES OF STAFF**

### 2.1 Medical Director and Executive Chief Nurse

**Responsible for:**

- Ensuring the WSFT provides a health care service to the local population that is accessible, safe and responsive to the needs of patients including those who may have specific needs arising as a result of a learning disability and/or autism.
- Assuring the WSFT Board and public that there are policies, processes and monitoring systems in place so that WSFT is compliant in its obligations under the Care Act, Equality Act, quality/safety standards and Government requirements.
2.2 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 particular 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 come into contact with 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.

2.3 Learning Disability Liaison and Safeguarding Adult Nurse

- The Learning Disability Liaison and Safeguarding Adult Nurse’s (LDLSAN) key role is to lead in the improvement of effective, accessible quality care delivery within the WSFT which is responsive to the needs of PWLD/A. The LDLSAN 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 and managing the interface between mainstream hospital services, specialist community services, private and voluntary services and families.

- The LDLSAN will lead on the formulation and support the implementation of the Learning Disability and Autism Strategy.

- The LDLSAN should be made aware of all PWLD/A who are admitted to the WSFT. When possible, the LDLSAN will visit every PWLD/A on admission to offer support, guidance and assess needs.

- The LDLSAN will advocate for the patient in relation to any reasonable adjustments that may be required to meet the needs of the PWLD/A.

- The LDLSAN will work closely with the Outpatient and Emergency Departments to ensure PWLD/A and their families/carers are supported whilst accessing these services.

2.4 Learning Disabilities Link Professionals

- The WSFT has a network of Learning Disabilities Link Professionals 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 link professional, who will receive additional training and supervision to support their role. Link professionals support the care planning and care of a PWLD/A and cascade information to their colleagues. [See Appendix A – Link Professional Role Description]
2.5 Clinical Staff

- All clinical staff are required to ensure that the needs of PWLD/A are met through individual assessment and care planning that takes into account 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 (See Appendix B) 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 patients advocate ensuring that they are given information about their condition and/or treatment in a way that they can understand in order 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.

SECTION 3 – CARING FOR PATIENTS WITH A LEARNING DISABILITY AND/OR AUTISM

3.1 Identification of patients

An electronic alert flag is available on both the Patient Administration System (PAS/HISS) and EPRO for ‘Learning Disabilities’ and ‘Autism’. If patients are not flagged in this way, these alerts can be added by staff who have the required level of authority as necessary. Staff should inform the LDLSAN when they are aware that a PWLD/A does not have an alert on their file. 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.

3.2 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 a number of 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:
  - 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.

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 LDLSAN is able to assist in the development of accessible information. There are a number of ‘easy-read’ resources available about a number of health issues, treatment methods and physical examinations available on the Trust intranet within the Learning Disability and Autism section and via the website: http://easyhealth.org.uk/.

There is also a ‘Hospital Communication Book’ available on the Trust intranet within the Learning Disability and Autism section as well 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 for this vital information. 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 on the Trust intranet).

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 number of other specialist 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.

There are a number of strategies which can assist in ensuring more effective communication when meeting a PWLD/A for the first time. [Please see Appendix C for more information on Strategies for Effective Communication].

3.3 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 Independent Mental Capacity Advocate (IMCA) Policy and Guidance [PP(11)223] and the Policy for consent to examination or treatment [PP(10)113].

3.4 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 interests 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.

3.5 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 LDLSAN.

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 wear their own clothes to theatre.
- Doing other investigations whilst individuals are under anaesthetic.
- Giving individuals a quiet place to wait away from the main waiting area.
- Giving the main carer a bleep so that the person can leave the ward/department (to help lessen anxiety/distress) and return when needed.
- 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.

3.6 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
- Is allowed to stay with the patient overnight if needed and suitable sleeping equipment is provided
- does not provide 24 hour care

Support for patients and carers

Family members.Carers who stay on the ward will be allowed access to the staff toilets and kitchen facilities and will be offered relief at least 4 hourly by the nursing staff so that they can have a break. This may include staff from the care home who are known to the patients and are employed to provide additional support or a parent or relative who should not be expected to provide 24-hour care. A ‘Carers Pack’ should be given to carers to enable recognition of their role and concessions to be applied.

3.7 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 in particular 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 also 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.

3.8 Partnership working

Multi-agency and multi disciplinary partnership working is essential to ensuring positive health outcomes for PWLD/A. The WSFT will support the development of strong partnership working with colleagues from the Norfolk and Suffolk Foundation NHS Trust (NSFT), Suffolk County Council and provider organisations. Working together with other health and social care providers such as GP’s and the Learning Disabilities Integrated Delivery Teams (IDT) 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 WSFT 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 LDLSAN 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. The LDLSAN is a member of the national and regional Access to Acute (A2A) network and is working with the NHS East of England team to develop services related to the Quality, Innovation, Productivity and Prevention Programme (QIPP) to ensure that PWLD/A across the region receive consistently high standards and equal access to health services.
3.9 Emergency Admissions

Visits to the Emergency Department (ED) can be extremely stressful for anyone and this is sometimes the experience for the PWLD/A and their carer. Whilst waiting for treatment, staff must ensure that the patient’s immediate needs are recognised and addressed as far as possible within the prevailing situation at that time and, if the patient is accompanied, that the carer’s views are taken into account to minimise the potential for stress and anxiety.

All PWLD/A should be seen as a high priority, however, there may be a delay in patients being seen if there are higher clinical needs in the department at that time - the decision rests with the Nurse in charge of the Department.

Waiting can be difficult for anyone who is ill or in pain, but for a PWLD/A, they may find the waiting extremely difficult and this can lead to additional problems, for example, ‘behaviours which may challenge’. ED staff should consider offering a quieter waiting area with clear information to the patient and their family/carer if they are with them. Reassurance and effective communication at this stage can often prevent perceptions of lack of awareness and consideration by staff of the patient’s needs.

Some reasonable adjustments which may be required:

- Consideration for reduction of waiting time (Fast Tracking)
- Find a quiet area for the person to wait
- Allow person and their carer to leave the ED and return when called
- Allow carer/relative to be present
- Early assessment and treatment of pain/discomfort

It must be recognised that in an emergency admission a PWLD/A may be particularly distressed due to the nature of the admission and may present with anxiety, agitation or challenging behaviour. The person may well be unable to articulate their level of pain and anxiety and be unable to express their symptoms. In this situation staff must contact the person’s relative/carer/social worker/community nurse/advocate as soon as possible. Advice and support should also be sought from the LDLSAN.

In the event that a PWLD/A is brought into the Emergency Department, the following issues must be considered:

- **Pain Management**: A PWLD/A may express the presence of pain through challenging behaviour (such as verbal/physical aggression to self/others/property, head banging, rocking, hitting parts of the body or similar signs of distress. It is important to find out what these behaviours mean and establish if they are part of the person’s normal presentation or related to their current circumstances. The person’s pain needs will need to be discussed on an individual basis, with input from the Pain team within the Trust and the LDLSAN. Information in the format of pictures and symbols can be obtained from [www.easyhealth.org.uk](http://www.easyhealth.org.uk).

- **Presence of other disabilities**: The person may have additional mental, physical and sensory disabilities or experience other co-morbidities such as epilepsy.
• **Communication:** Communication will be particularly difficult if the person is distressed and every effort must be made to explain procedures in a quiet and controlled manner and use supportive communication aids where possible.

The ‘Hospital Communication Book’ should be used to assist in communicating and the LDLSAN should be contacted to assist with communication.

• **Environment:** The Emergency Department is a challenging environment for those without a disability and may present a particularly frightening environment to a PWLD/A who is unable to understand what is happening to them or simply has a fear of hospitals or unfamiliar places. Where possible it is advisable to utilise a cubicle where privacy and a slightly quieter environment can be provided.

Staff admitting a PWLD/A via the Emergency Department, the Emergency Assessment Unit (EAU) or other routes, must advise the Patient Flow Team and the receiving ward of the patient’s enhanced needs, prior to the formal assessment process.

An **Emergency Department Care Pathway** has been developed for PWLD/A [Appendix D].

### 3.10 Elective Admissions

When attending the Pre Assessment Clinic and on admission, the PWLD/A or their 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 in the Learning Disabilities Resource Folder on every ward/department or from the Learning Disability pages on the Trust intranet. Copies can also be obtained from the LDLSAN.

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. A summary of this discussion must be documented in the patient’s healthcare record.

The assessment will include:

- Swallowing difficulties or dietary needs
- Sensory disabilities such as hearing or visual impairment
- Specific communication needs
- Routine medication, particularly those related to managing epilepsy
- Pain management
- Transport needs
- Special possessions to bring into hospital
- Discharge arrangements

Where possible the 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.

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.

A Theatre / Recovery Care Pathway has been developed for PWLD/A [Appendix E].

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

3.11 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.
When support is provided by the care provider they should be instructed to send an invoice to the Creditor Payment Officer in the WSFT Finance Department for re-imbursement.

[SEE THE TRUST INTRANET FOR MORE INFORMATION ON THE FUNDING FOR CARE PROVIDERS PROTOCOL]

3.12 Transfers of Care

Effective communication of information between professionals, family, carers and support workers is essential during transfers of care. Individuals with Health/Hospital Passports and/or Health Action Plans should have these updated before all transfers of care and staff receiving the patient should be made aware of this information. When a PWLD/A is being transferred from another area of the hospital, the receiving Ward Manager or senior nurse in charge has responsibility for ensuring all relevant information regarding risk, support needs and reasonable adjustments required are gathered and acted upon.

An Elective Admission Pathway has been developed for PWLD/A [Appendix F].

3.13 Outpatients Appointments

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

Where possible the PWLD/A and/or the 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.

- **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 in order 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. If a follow up appointment is not offered, care arrangements should be discussed and negotiated with the LDLSAN if involved who can liaise as necessary with the GP and specialist community services.

An **Outpatients Pathway** has been developed for PWLD/A [Appendix G].

### 3.14 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 paragraph 3.11.

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.
3.15 Maternity Care

Increasingly there is a need for people with a learning disability to access maternity services. Around 7% of adults with a learning disability are parents, most having a mild to borderline learning disability, which may mean they do not have a formal diagnosis and may be difficult to identify. Studies show that around 40% of parents with a learning disability do not live with their children. Children of parents with a learning disability are more likely than any other group to be removed from their parents care. Fear of the involvement of social care services may lead to the avoidance of maternity care. Therefore good support mechanisms and antenatal education are vital for parents with learning disability who will have their parental competence assessed.

Issues in pregnancy

One in three pregnant women with a LD have reported moderate to severe levels of stress, anxiety and depression. This may be for a number of reasons including social isolation, poverty, literacy issues and difficulties with communication. They may face much opposition to their desire to parent; they may even face pressure to have their pregnancy terminated.

The babies of mothers with Learning Disability are at increased risk of poor birth outcomes including:

- Premature birth (28%)
- Low birth weight (22%)

Reasonable adjustments are required to support accessibility of maternity services for example:

- extra time and support at appointments
- opportunity to have information repeated
- information about pregnancy and birth choices presented in a way that is easy to understand and utilising easy-read resources
- involving family carers and advocates

To ensure that women with learning disabilities and/or autism have the necessary support, advice and guidance when accessing the maternity services at the West Suffolk Hospital a specific Maternity Care Pathway has been developed by the Children and Maternity services in collaboration with the LDLSAN [See Appendix H].

3.16 Discharge from Hospital

In addition to the procedures laid down in the WSFT’s Discharge Planning Policy PP(11)062 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 on a daily basis 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 LDLSAN 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 LDLSAN 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. The LDLSAN should also be involved in the discharge of PWLD/A.

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, Dosset boxes, boxes with larger print and additional accessible information leaflet etc. Clinical 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 with regard to 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 the Independent Mental Capacity Advocate (IMCA) Policy and Guidance [PP(11)223].]
A Discharge Planning Pathway has been developed for PWLD/A [Appendix I].

3.17 Patient Feedback

Easy read versions of patient feedback forms have been developed for PWLD/A and their family carers. These should be used alongside the WSFT Generic feedback process and are available on all wards and departments. Copies can also be downloaded from the Learning Disability and Autism section on the Trust Intranet.

SECTION 4 – TRAINING AND EDUCATION

The Trust has a commitment to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for PWLD/A. Ensuring that all staff have appropriate skills, knowledge and attitudes is key to ensuring that the agreed pathways deliver high quality care for each individual. Training and education is coordinated and delivered by the LDLSAN and is aimed at all staff across the Trust.

All Registered Nurses and Nursing Assistants are provided with Learning Disability and Autism Awareness training on induction. Additional and bespoke training and education is also provided to ensure that appropriately skilled staff are available in all areas.

The Trust has a framework in place which aims to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for PWLD/A. The training is coordinated and delivered by the Learning Disability Liaison and Safeguarding Adult Nurse and is aimed at all staff across the Trust.

The framework offers three levels of training starting from Level 1 - awareness raising at induction through to specific skills and knowledge training for ward and departmental based Learning Disability Link Professionals at Level 3.

Level 1 - Learning Disability and Autism Awareness for all staff at Trust induction (mandatory attendance).

Level 2 - Learning Disability and Autism awareness for non-clinical and clinical staff with face to face contact (One-off mandatory training session).

Level 3 - Learning Disability Link Professional Training and Action Learning Sets (Bi-monthly training).

Learning Disabilities and/or Autism awareness training is to be included in the mandatory training matrix.

MONITORING OF COMPLIANCE

An annual audit of Reasonable Adjustments will be undertaken by the Learning Disability Liaison Nurse to monitor compliance with this Policy. In addition, the Policy will be audited against the actions within the Learning Disability and Autism Strategy and the Learning Disability Annual Improvement Plan. Patient Feedback Survey information will also be utilised to monitor compliance.
REFERENCES


ACKNOWLEDGEMENTS

Grateful thanks to the Ipswich Hospital NHS Trust for their willingness to share their policy on which this document is based.

SECTION 5 - DOCUMENT CONFIGURATION INFORMATION

<table>
<thead>
<tr>
<th>Author(s):</th>
<th>Paul Hunter, Learning Disability Liaison &amp; Safeguarding Adult Nurse</th>
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<tbody>
<tr>
<td>Other contributors:</td>
<td>Sam Bower, Deputy Chief Nurse, Matrons, Ward/Department Managers</td>
</tr>
<tr>
<td>Approvals and endorsements:</td>
<td>Trust Executive Group</td>
</tr>
<tr>
<td>Issue no:</td>
<td>2</td>
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APPENDIX ITEMS

APPENDIX A - LEARNING DISABILITY LINK PROFESSIONAL ROLE

APPENDIX B - HEALTH PASSPORT

APPENDIX C - STRATEGIES FOR EFFECTIVE COMMUNICATION

APPENDIX D - EMERGENCY DEPARTMENT CARE PATHWAY

APPENDIX E - THEATRE / RECOVERY CARE PATHWAY

APPENDIX F - ELECTIVE ADMISSION PATHWAY

APPENDIX G - OUTPATIENTS PATHWAY

APPENDIX H - MATERNITY CARE PATHWAY

APPENDIX I - DISCHARGE PLANNING PATHWAY
Role purpose

- To promote and act as a principal point of contact for patients with Learning Disabilities and/or autism (PWLD/A), their families, department staff and the learning disabilities liaison nurse
- To act as a resource, disseminate information and be an advocate for patients with PWLD/A that access services in their area.
- To act as a resource to other staff within their unit for safeguarding people with a learning disability.

Key duties and Responsibilities

- To disseminate and cascade updated information about PWLD/A: Ensuring all staff are aware of the learning disability resource folder available on the Trust intranet.
- To contribute towards the area/department compliance with the Equality Act (2010) Raising understanding of what constitutes a reasonable adjustment.
- To encourage the participation and uptake of staff to complete the training packages for learning disability.
- To develop as required accessible information relevant to their area. To signpost other staff to the resources available to support the development of accessible information e.g. photo symbol bank, easy health website.
- To ensure that patient information leaflets are displayed in their areas that give information on PALS and complaints and that easy read versions are also displayed.
- Act as the patient’s advocate and support colleagues to understand and use the Trust consent policy, Mental Capacity Act 2005 and Human Rights Act 1998.
- To offer support and advice to relatives and carers using recommendations in the Trust carers policy and learning disability policy.
- To understand barriers to communication and act as a resource to staff for using alternative methods or tools for communication.
- To assist staff to identify risks for people with a learning disability or autism.

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

**Role specification**

| Qualifications | 
|---|---|
| 1. Trust employee | Essential |

**Knowledge and experience**

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Has attended the Trust Learning Disability and Autism Awareness session.</td>
<td>Essential</td>
</tr>
<tr>
<td>2. Working in the clinical area for one year.</td>
<td>Desirable</td>
</tr>
<tr>
<td>3. Previous experience working with learning disabled or vulnerable people.</td>
<td>Desirable</td>
</tr>
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</table>

**Skills and abilities**

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<tr>
<td>1. Interest in learning disability and autism.</td>
<td>Essential</td>
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<tr>
<td>2. Enthusiasm for improving services PWLD/A</td>
<td>Essential</td>
</tr>
<tr>
<td>3. Ability to be creative in supporting reasonable adjustments.</td>
<td>Essential</td>
</tr>
<tr>
<td>4. Good communication skills.</td>
<td>Essential</td>
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<tr>
<td>5. Uses the email system to access disseminated information.</td>
<td>Essential</td>
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**Training and development**

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<thead>
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<tbody>
<tr>
<td>1. Regularly attend link practitioner meetings.</td>
<td>Essential</td>
</tr>
<tr>
<td>2. Keeps updated on current developments in learning disabilities/autism</td>
<td>Essential</td>
</tr>
</tbody>
</table>
APPENDIX B - HEALTH PASSPORT

My Health Passport

Please make sure that this stays with me.
You can keep a copy for my file.

My name is:
I like to be called:
My date of birth:
My NHS no:

This is me

Things I like

Things I don't like

Contact details for the person who knows me best.
How to support me with **Communication**:

<table>
<thead>
<tr>
<th>Behaviours which might challenge, including triggers and how best to support me.</th>
</tr>
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<table>
<thead>
<tr>
<th>Health and Sensory Needs</th>
<th></th>
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<tbody>
<tr>
<td><strong>Sight</strong> – any difficulties or aids</td>
<td></td>
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<tr>
<td><strong>Hearing</strong> – any difficulties or aids</td>
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<table>
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<tr>
<th>Known allergies</th>
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<table>
<thead>
<tr>
<th>Epilepsy – a description of my seizures</th>
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<table>
<thead>
<tr>
<th>Medical interventions (e.g. how best to take my blood, give me injections)</th>
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</table>

<table>
<thead>
<tr>
<th>Medication – how I like to take it</th>
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<tbody>
<tr>
<td>I prefer Liquid / Tablet</td>
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</table>
A person’s capacity to understand and communicate can be affected by a number of factors including anxiety, pain, distress, unfamiliar people and environments. People with a learning disability and/or autism may also be unable to adequately describe their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell. There are a number of strategies which can assist in ensuring effective communication when meeting a person with a learning disability and/or autism for the first time.

**INITIAL INTERACTION – ON FIRST MEETING PERSON**

- When unsure of ability to understand assume competence & then adjust accordingly. (This is more appropriate and respectful than assuming a lack of understanding).
- Ensure you have the person’s attention.
- Speak to the individual first; include the family carer/support worker as necessary.
- Inform the person that you are going to speak to their relative/carer/support worker.
- Continue to involve them using eye contact.
- Address the person by their preferred name, to support the person in recognising you are speaking to them.
- Find out from family members/carers how best to communicate with the person (verbally, sign language, communication aids, etc) and make sure this information is passed onto colleagues.
- Gather information from family members or carers as appropriate, but seek permission from the person and continue to include them in the dialogue.

**THE ENVIRONMENT**

- Consider the environment - avoid too many distractions. A quiet, naturally lit environment will support communication.
- Use environmental and contextual cues where appropriate.
- Ensure the environment is well lit in order to enable a person to maximise their visual potential.

**USE COMMUNICATION AIDS**

- Where appropriate make use of communication aids - for example picture symbols, photographs. Some people have their own individualised communication passport, which usually contains photographs and picture symbols which support communication.
- Use ‘objects of reference’ to support understanding e.g. show a cup when you are offering a drink.
- Show the person any equipment being used.
- Show the person what is going to happen either simulating on yourself, a colleague or a family member/carer if present.

**VERBAL COMMUNICATION**

- Speak slowly and clearly.
- Use short, plain sentences, containing one piece of information at a time, pausing after each one.
- Check your pitch and tone, for some people who are hyper-sensitive loud voices can be frightening.
- Avoid the use of words which can have a literal meaning e.g. “Wait a minute”, “take a seat”.
- Avoid using jargon and figurative speech as it may lead to confusion as many people are literal in their understanding.
- Avoid over-long descriptions and clichés.
- Explain any difficult or unfamiliar words. For example: “I will send you for an x-ray” it may be better to say; “we will need to take a picture of your arm”.
- When asking a question, allow time for the individual to process the information, there may be a delay in their response.
- Use open ended questions to assess a person’s understanding and rephrase the question if necessary, as repeating the same question rarely improves understanding.
- When giving an instruction, tell the person what you need them to do one step at a time, once that task is completed give the next instruction.
- Avoid offering too many choices at a time, this may lead to confusion.
- When having ‘vital conversations’ such as diagnosis and treatment plans ensure that the person has support from a family carer/support worker.
- Check understanding as you communicate. Ensure you understand what is being communicated back. Don’t just ask “do you understand?” as this may just provoke a “yes”/”no” answer. Check understanding by asking the person to repeat back in their own words what has been said.
- If the person has not understood, try rephrasing the information.
- Explain what you are doing, and do one thing at a time where possible.

**NON-VERBAL BODY LANGUAGE**

- Be aware of facial expressions and non-verbal body language - Don’t expect the person to give non-verbal feedback you are used to, but be sensitive to what you do see.
- Use gestures, body language and facial expression to supplement words but be aware that these may have different meanings across cultures.
- Some people may misunderstand eye contact, body language and gesture, s/he may lack awareness of ‘personal space’ or be fearful of people invading their ‘personal space’.

**SENSORY IMPAIRMENTS**

- Be aware of any additional disabilities such as hearing or visual impairment.
- Initiate conversation with someone who has a visual impairment by lightly touching their arm and using their name.
- Move in front of a person with a hearing / visual impairment before communicating with them, rather than touching from behind.
- Sit in front of, or to the ‘better side’ of a hearing impaired person.
- If the person lip reads, ensure you position yourself in the brightest part of the room – do not sit / stand in front of a window as you may be in silhouette which will make it difficult for the person to read your lips.
- Do not shout at the person because they do not speak or have a hearing impairment.

**ACCESSIBLE INFORMATION**

- Consider what ‘Easy Read’ information may be available and utilise this where appropriate.

**GENERAL GUIDANCE**

- Check if the person has a ‘Health / Hospital Passport’, communication passport or equivalent and utilise this to obtain information about how the person communicates.
- Take your time to communicate well and listen.
- Be prepared for pauses and silences. People with learning disabilities/autism may have difficulty processing information and formulating a response.
- Allow the person to say as much as possible, however long it takes.
• If speech is difficult to understand – don’t pretend that you have understood:
  ➢ Be polite & apologetic
  ➢ Ask person to repeat it again (slower, using different words, get the person to show you what they mean).

• It is always important to identify:
  ➢ How the person indicates “yes” and “no”.
  ➢ How the person indicates pain, discomfort, anxiety, distress and expression of emotions.
  ➢ What certain behaviours might mean.
  ➢ Personal interests / likes and dislikes – knowing these can help develop the initial relationship with the person.

  ➢ Be honest and take responsibility for communication breakdowns (e.g. I'm sorry, I'm not sure I understanding what you're telling me - Never pretend to understand!)

Point to Remember: receptive language may be better than expressive language or vice versa.

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]
A person with a Learning Disability (LD) and/or autism presents at the Emergency Department (ED). Reception staff to check if person has an alert on the system and fast track or offer quiet place to wait if required – ask person or carers what additional help or support may be needed.

**Examples of Reasonable Adjustments:**
- Involve carers.
- Consider a quiet waiting area / Side room or letting the person wait outside.
- Fast-track patient if they cannot tolerate a noisy/busy environment.
- Find out what additional help is needed.
- Ensure ‘Health Passport’ in place – if not give one to carer to complete.
- Use words patient can understand.
- Explain everything using simple words & one piece of information at a time.
- Find out how patient communicates (especially ‘yes’ ‘no’ and pain).
- Consider using Ametop or similar if taking blood or inserting a venflon.

**Triage the Patient**
- Nurse to ensure patients safety and deal with immediate health care needs.
- Can the patient be fast-tracked to ward F8 or preferably a base ward to prevent anxiety and distress caused by multiple moves?
- Are family carers or paid carers with the patient? If not, do they need to be? Carers usually have essential information and need to be involved in assessment.
- Has the patient brought in any information about their support needs (e.g. Health/Hospital Passport)? If the patient does not have one, offer a blank Health Passport to fill in for future visits and admissions.
- Consult with support staff / Family and the Health/Hospital Passport regarding the person’s usual presentation & means of communication (in particular relating to expression of pain/anxiety).
- Some people with LD/Autism can become more withdrawn when injured or unwell & others may become more vocal & physical when expressing pain.
- Does the person usually have PRN medication when anxious? (If so, consider administration).

- Gather all relevant information.
- Identify the main carer/guardian and contact them as soon as possible.
- Ensure all information about the patient’s needs is handed over to the doctor.
- Refer to the Learning Disability Liaison Nurse (Extn. 2750 or Bleep 221).

- Explain treatment options / procedures – Use *Easy Read leaflets where possible to explain things to enable understanding and informed consent.
- If patient is unable to give informed consent or ability to do so is questioned, refer to the Trusts Policy on The Mental Capacity Act 2005 and Independent Mental Capacity Advocate (IMCA) Policy and Guidance.
- Any care and treatment carried out in the patient’s ‘Best Interests’ must be recorded clearly in the patient’s notes.

**TREAT**

**Is the patient going to be admitted?**

**Is the patient to be referred for an Out-Patient appointment?**

- Ensure all referrals include information about the patient’s learning disability / autism & additional needs (e.g. hoist, 1:1 care)
- Allow extra time to explain any aftercare & give *Easy Read leaflets as necessary. Ensure patient & carers have understood.

- Advise receiving ward of any potential additional care needs or reasonable adjustments that the patient may require e.g. side room.
- If carers are to be present – find out how often, & make provisions for them to stay with the patient.
- Alert ward to any issues around capacity & consent.

* Easy Read advice and leaflets available on LD/Autism Section of Trust Intranet and at: www.easyhealth.org.uk

Source: Anthony Green
Issue date: 01.02.16
Status: Approved
Review date: 01.02.18
Document reference: PP(16)275
APPENDIX E – THEATRE / RECOVERY CARE PATHWAY

Preparation for Theatre
The following care elements should be discussed during the pre-assessment appointment:

CONSIDER:
1. The patient’s previous experience of anaesthesia and surgery
2. Behaviour patterns during recovery of anaesthesia
3. Patient’s communication needs. Refer to patients Health / Hospital Passport or main carer for these.

The Learning Disability Liaison Nurse should be informed of the patient’s admission date in order to offer support to the patient, his/her carers and colleagues.

Pre- Assessment Unit staff will put all relevant information onto OPERA and they should also contact the Operating Theatre Co-ordinator (Bleep 538) well in advance where possible to discuss any specific patient needs. This information should also be conveyed to the Recovery Room staff.

Surgeon and Anaesthetist to visit patient on the ward pre-operatively to meet and assess the patient and carers specific needs where appropriate. Consider if the patient needs to go straight to the anaesthetic room.

Explain procedure through use of visits, photos – this will assist in gaining informed consent. The process will be explained to the patient and carer before the transfer to theatre, so they know what to expect.

Is pre-medication needed? Is the patient frightened of needles? Is Ametop or similar required?

Going to Theatre
- Discuss with the carers the best way to transfer the patient to theatre. On trolley, bed, wheelchair, buggy or walking? (Dependant on whether patient has had a pre-med).
- Agree most appropriate way to anaesthetise patient – gas induction or cannula.
- Arrange for the patient to be accompanied to theatre and into anaesthetic room by someone known to them, who will then be able to stay until the patient is anaesthetised.

Recovery
- Once the procedure is complete the recovery nursing staff should contact the ward to notify the main carer that the procedure is complete and invite the main carer back to the Recovery Room when the patient is coming round.
- Where possible, the patient should be escorted back to the ward nurse who is known to them, along with their carer.
- Contact the Learning Disability Liaison Nurse for support (Extn. 2750 Bleep: 221).

Reasonable Adjustments to consider:
- Does the patient need to be put into a theatre gown? Can the patient remain in their own clothes to reduce anxiety / distress?
- Could the ID wristband be applied when the patient is anesthetised?
- Does a clear care plan need to be agreed prior to theatre so everyone is clear of their roles and responsibilities?
- Parents/main carers to accompany patient to theatres and recovery.

For further advice/guidance contact the Learning Disability Liaison & Safeguarding Adult Nurse on 2750 Bleep: 221
APPENDIX F - ELECTIVE ADMISSION PATHWAY

Planned admission to hospital

Admissions Team:
Inform Pre-assessment Unit & Learning Disability Liaison Nurse if referral indicates patient has a LD and/or Autism

Pre-assessment Appointment

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

Yes

Ward staff to discuss with Operational /Directorate Manager and arrange additional resources as per policy (See LD/Autism Policy and 1:1 Policy).
Use *Easy Read* leaflets where possible to explain things.

MEDICATION
Specific attention should be given to the patient’s medication regime including preparation, times and method of administration (these may have been tailored to the individual patient’s needs and should continue while in hospital).

No (Support as appropriate)

Yes

No

DISCHARGE PLANNING (see Discharge Planning Pathway)

- Patients with LD/Autism often have complex discharge planning needs.
- Discharge planning will begin at the time of admission with an estimated discharge date.
- Ensure that all aspects of the patient’s care are discussed & an action plan agreed to meet the needs of the patient at discharge.
- Ward staff & Discharge Planning Team to identify appropriate community support has been identified and arranged.
- Ensure that the Discharge Summary is given to the patient and main carer prior to discharge.
- Ensure main carer is aware of any medication changes or that any new medication regime is fully understood & checked at point of discharge.
- If no changes to medication & patient has Dossett box NO TTO’s to be arranged as patient will use own supply.

Liaison Nurse to make contact with the patient and main carer prior to admission:
- Invite them to attend the ward prior to admission for familiarisation and to reduce anxiety.
- Discuss admission arrangements.
- Offer/Review Health Passport and care plans (if available).
- Discuss current care needs and specific aids/equipment used.
- Seek consent for carer involvement during admission.
- Negotiate level of support by carer during admission (e.g. staying with patient throughout admission).

Remember:
- Consider mental capacity and DoLS.
- Follow the five principles of the MCA 2005.
- Presume capacity.

Can the patient:
- Understand the information relevant to the decision?
- Retain the information long enough to make the decision?
- Use/weigh up the information to make the decision?
- Communicate their decision (by any means)?

➢ Ensure the appropriate Consent Form is used and document clearly.
➢ No one can consent for someone over 16 years of age.

Pre-assessment Nurse:
- Does patient have a LD/Autism?
- Does patient have a 'My Health / Hospital Passport? If not, offer 'My Health Passport' for completion.
- Consider what reasonable adjustments are required e.g. side room, 1st on theatre list, carer to stay, visit to the ward etc.
- Add LD/Autism alert to PAS/HISS with consent if able.
- Liaise with admitting ward to advise of additional needs.
- Check if patient has a Social Worker or Community Nurse – contact to obtain further information.
- Refer to Learning Disability Liaison Nurse for advice and support Extn: 2750 Bleep: 221 Email: paul.hunter@wsh.nhs.uk
- Inform the patient/carer of the LD Liaison Nurse role & give them the LD Liaison Service Leaflet.

West Suffolk NHS

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Prior to the Outpatient Appointment
If a Learning Disability and/or Autism is identified on referral letter from GP/Clinician or on PAS/HisS:

1. Contact patient, their carer/support worker to discuss details of the appointment and any specific needs/resources required.
2. Request the patient brings in his/her Health/Hospital Passport and Health Action Plan to the appointment.
3. Invite the patient or main carer to make contact with the Clinic Nursing staff.
4. 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.

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.

Inform the Learning Disability Liaison & Safeguarding Adult Nurse of patient’s appointment. Extn: 2750 Bleep: 221 Email: paul.hunter@wsh.nhs.uk

Follow-up appointment given?
Ensure written down on card with date, time & month separately [e.g. 1pm (afternoon) 2nd May 2015].

Before leaving the clinic
If the patient does not have one, offer a blank Health Passport to fill in for future visits and admissions.
Inform the patient/carer of the LD Liaison Nurse role and give them the LD Liaison Service Leaflet.
Ensure patient and carer understand the outcome of the consultation.
If follow up appointments required establish further care requirements.

* Easy Read advice and leaflets available on LD/Autism Section of Trust Intranet and at: www.easyhealth.org.uk

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

YE

NO

Ensure detailed handover is given to the relevant staff.

Make the LD Liaison & Adult Safeguarding Nurse aware so that specialist support/advice can be offered.

Keep patient and carers informed and involved.
Pregnancy Disclosed

LD known or disclosed. Refer to LD Liaison Nurse and/or current Community LD Nurse.

Liaise with LD Liaison Nurse and Community LD Nurse and arrange to accompany for booking appointment

1. Advise Domestic Abuse
2. Assessment of needs (usually CAF)
3. Consider Social Care thresholds.
4. Share CAF with Community LD Nurse and Health Visitor

Follow Pre Birth Plan (PBP)
Standard Post Natal care plus PBP
- Continue Parenting Skills Teaching
- Pre discharge planning meeting when appropriate
- Detailed communication – all professionals aware of discharge plan

Pre Birth Planning Meeting:
- ensure patient passport completed
- birth plan - parents
- birth plan – social care

Copy of plan to:
- Parents
- All Professionals
- Notes
Include p/n planning and special carer arrangements if necessary.

Children’s Social Care referral if safeguarding concerns

LD / Autism Unknown

LD / Autism suspected. Refer to LD Liaison Nurse. Consider use of LD screening tool

Routine Individualised Anti Natal Care

Screening tool did not indicate presence of learning disability/autism

Individualised care through pregnancy to involve
- Parents/Carer
- Community Midwife
- LD Liaison Nurse
- Community LD Nurse
- Social Worker if appropriate
- Children’s Centre Staff
- Hospital midwives
- Individualised parenting preparation
- Patient Health Passport (if not already in place)

At home – may require extended midwifery visiting (up to 28 days):
- Routine post natal care continues
- Assessment and support with parenting continues as per plan
- Liaise with other professionals – Detailed handover to Health Visitor
- Contraception – Discussed and arrangements in place.
APPENDIX I – DISCHARGE PLANNING PATHWAY

Patients with Learning Disability (LD) and/or Autism - planning for discharge:

Many patients with learning disabilities/autism will have complex discharge planning needs therefore consider the need for a Multi-disciplinary planning meeting prior to discharge – include the Specialist Discharge Planning Team (Tel: 3369/3629) and the LD Liaison Nurse (Tel: 2750 Bleep: 221).

Specialist services such as the Learning Disability Liaison Nurse and the Community Integrated Delivery Team (IDT) play an important role in helping Acute Hospital staff understand the needs of people with a learning disability and should therefore be involved in MDT meetings.

Ensure carers have visited the patient & confirmed that they are happy to take the patient home – make sure they have all relevant information regarding any treatment, procedure and aftercare arrangements.

Liaise with the patient & their main carer whether a morning or afternoon discharge is preferable. Keep the patient & main carer informed if there are any delays.

Problems with Rapid Discharge:

‘Discharge from Hospital: Pathway, Process and Practice’ (DOH 2003) identifies that the emphasis on rapid discharging means some people with a learning disability/autism are returning to the community when their needs have not been identified, treated or met.

It is important to understand that many paid carers who support people with a learning disability/autism do not have any nursing or health based training and will therefore need follow-up support and advice if they are to provide appropriate aftercare for the patient.

Family carers of people with a learning disability/autism may be older people - Do they have the physical ability to manage additional health needs?

Discharge paperwork:

Most patients who have a learning disability/autism will have limited reading skills. It is therefore important to explain to the patient any aftercare information, such as new medication, follow up appointments etc. Concept of times may be difficult for individuals when taking new medication.

Patient to be given full explanation of any additional tests or investigations. Use *Easy Read* leaflets where possible to explain things.

For further advice or guidance contact the Learning Disability Liaison & Safeguarding Adult Nurse on 2750 Bleep: 221

Integrated Delivery Team Contact Details:

Bury South Team:
01284 733188

Bury North Team:
01638 558650

Issues to consider before discharge:

Does the person need extra time to recover because of additional physical and/or mental health problems?

Can the individual realistically return to their previous home environment?

Can carers deal with additional health needs?

Does the person have adequate support in place at home?

Has the patient been given all the relevant information they need on discharge in a format that he/she will understand?

* Easy Read advice and leaflets available on LD/Autism Section of Trust Intranet and at: www.easyhealth.org.uk

Refer to the Trust intranet site for further information and consider if a person may need additional support such as homecare, in order to successfully follow up aftercare advice.