

Learning Disabilities & Autism Spectrum Disorder Policy

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What is in this policy?	
<p>This policy provides standards and guidance for all staff within University Hospitals Bristol and Weston NHS Foundation Trust (the Trust) to help ensure that a high standard of care is provided, communication between patients, carers and health professionals is effective and that any additional care needs and resources that may be needed to support individual patients is in place.</p>	

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- **Stakeholder Group** can include any group that has been consulted over the content or requirement for this policy.
- **Steering Group** can include any meeting of professionals who has been involved in agreeing specific content relating to this policy.
- **Other Groups** include any meetings consulted over this policy.
- **Policy Assurance Group** must agree this document before it is sent to the **Approval Authority** for final sign off before upload to the DMS.

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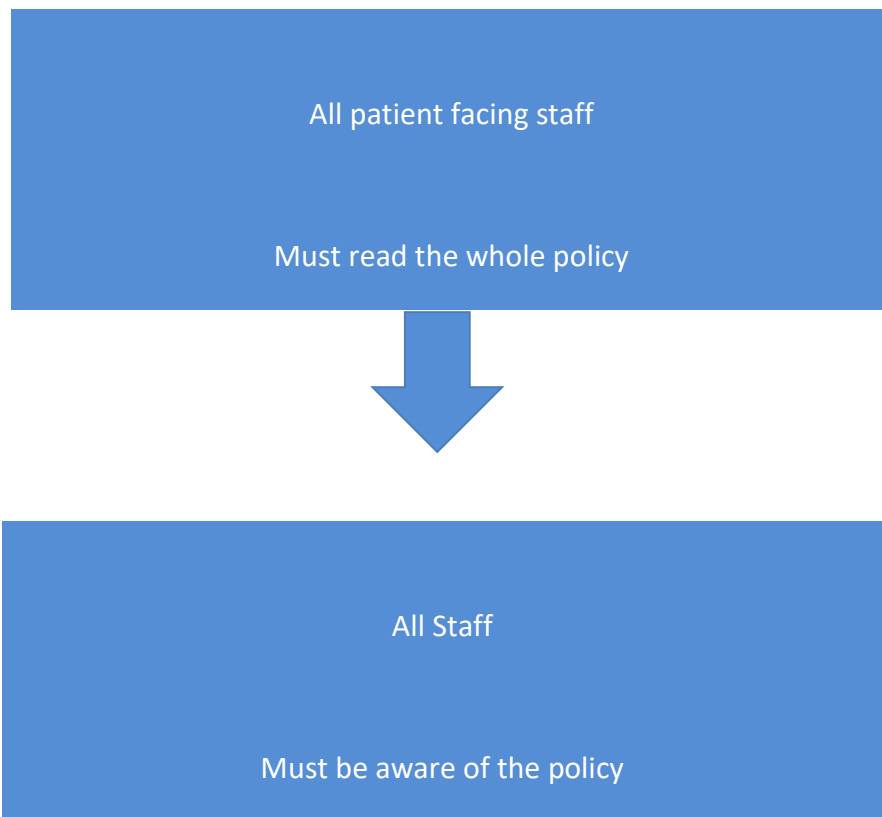
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Do I need to read this Policy?



1. Introduction

University Hospitals Bristol and Weston NHS Foundation Trust (the Trust) aims to meet the needs of the population and is committed to providing a discrimination free environment for any patient, visitor or employee who may have a protected characteristic under the Equality Act (2010).

This policy aims to set out how people with a learning disability (LD) and/or autism will be supported when accessing services provided by the Trust.

Current estimations report that approximately 1.3 million people are diagnosed with a learning disability in the UK, this equates to 1:50 or 2% of the population (Foundation of People with Learning Disability, 2018). With advances in healthcare, specifically neonatal care for premature babies and recognition that people with a learning disability are living longer, this estimated number is expected to continue to rise. It must be recognised 49% of deaths in 2021 were considered avoidable in relation to 22% of the general population (LeDeR 2022).

“Healthcare for All” (2008) and “Six Lives” (2009) highlighted that a lack of awareness in the NHS of people with learning disability. They further added that the significant risks these individuals were exposed to needed consideration, with reasonable adjustments put in place to support equal access and care. Following further publications of Death by Indifference – 74 deaths and Counting (2012), the Confidential Inquiry into Premature Deaths of people with Learning Disabilities (2013) and currently the LeDeR Mortality Reviews (2020-21) it is clear that staff providing care to people with a learning disability need to be informed and know how to communicate and address specific care needs.

In June 2018 NHS Improvement produced a new document ‘The learning disability improvement standards for NHS Trusts’. It highlights that people with learning disabilities, autism or both and their families and carers should be able to expect high quality care across all services provided by the NHS. They should receive treatment, care, and support that are safe and personalised; and have the same access to services and outcomes as their non-disabled peers.

These standards provide a benchmark against which all trusts, be they universal or specialist healthcare providers, can measure their performance in delivering services to people with learning disabilities, autism or both, so driving quality improvement.

The Equality Act (2010) previously Disability Discrimination Act (1995) aims to end the discrimination that many disabled people face. It now gives disabled people rights in the areas of employment, education, access to goods, facilities and services. The Act requires public bodies to promote equality of opportunity for disabled people.

The Confidential Inquiry into Premature deaths of people with a Learning Disability (CIPOLD) (2013) identified three key factors that remain current today:

- (a) Barriers to accessing services; GP services not referencing the learning disability of patients referred to services, hospitals not flagging those patients with a known

- learning disability, thus reasonable adjustments not being made to accommodate these individuals;
- (b) Significant delay or difficulty obtaining diagnosis, further investigation and/or specialist opinion due to (a);
- (c) Lack of adherence to Mental Capacity Act (2005) by healthcare professionals.

2. Purpose

The purpose of this policy is to set out how patients with learning disabilities and/or autism, their carers, family or friends are supported when accessing services provided by the Trust. It aims to ensure that the care they experience is safe, caring and effective and that staff are sighted on individuals to ensure care is person-centred and meets their individual needs.

This policy is designed to:

- (a) Provide guidance to staff about what “reasonable adjustments are”;
- (b) Clarify the roles and responsibilities of all staff groups within the Trust on providing care for patients with learning disabilities and/or autism;
- (c) Signpost specialist teams, resource and support for staff to support patients with learning disabilities and/or autism.

3. Scope

This policy relates to all permanent and temporary employees, volunteers, agencies and agency staff working for and on behalf of the Trust. The learning disability and/or autism team are employed by Sirona care and health services and provide an in-reach service to UHBW patients and employees.

4. Definitions

4.1 Learning Disability

Valuing People: a new strategy for learning disability for the 21st Century (Department of Health, 2001) defined a learning disability as:

- A significantly reduced ability to understand new or complex information and to learn new skills;
- A reduced ability to cope independently;
- An impairment that started before adulthood (before the age of 18 years) , with a lasting effect on development.

This is not to be confused with a learning difficulty (an educational learning need such as dyslexia, Attention Deficit/Hyperactivity Disorder etc.)

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4.2 Autism

Autism is not defined as a learning disability but can be an additional diagnosis for someone with an existing learning disability or a stand-alone diagnosis. Reasonable adjustments may be required regarding communication, the environment (often over stimulating) and sensory overload; both physical and auditory.

NHS England identify that autism is a spectrum and that every autistic person is different. Autism is not a medical condition with treatments or a cure but some people may need help/support. People with Autism in the main have expressed that they wish to be called Autistic. This is the preferred terminology.

Asperger's is used by some people to describe autistic people with average or above average intelligence; however Autistic Spectrum Disorder is the preferred terminology.

Autistic people may:

- Find it hard to communicate and interact with other people.
- Find it hard to understand how people think or feel.
- Find things like bright lights or loud noises overwhelming, stressful or uncomfortable.
- Get anxious or upset about unfamiliar situations and social events.
- Take longer to understand information.
- Do or think the same thing over and over.

4.3 Behaviours that cause distress

Distressed behaviour includes what would normally be considered physically aggressive behaviour, such as slapping, biting, spitting or hair pulling, the list is not exhaustive, the Trust in line with people with a learning disability and/or autism use this terminology rather than challenging behaviour or behaviours that challenge. Behaviours that cause distress can mask what is actually happening; pain, anxiety, constipation, hunger etc. Staff are required to look beyond the behaviour, read their hospital passport, communicate with those that know the person well, listen and watch the patient, think; what are they trying to tell you?

4.4 Carers

A carer is anyone, including children and adults, paid or unpaid, who looks after an individual, be they family member, partner, friend or employer who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support (NHSE 2018).

4.5 Best Interests

Any act done, or decision made on behalf of an adult lacking capacity must be in their best interests. This can cover financial, health and social care decisions (MCA 2005). A best interest decision should take into account:

- (a) Past and present wishes and feelings;
- (b) Beliefs and values that may have influenced the decision being made, had the person had capacity;
- (c) Other factors that the patient would be likely to consider if they had capacity.

4.6 Mental Capacity

Mental capacity' means being able to make your own decisions (Mental Capacity Act, 2005). A person with a learning disability may lack the capacity to make major decisions, but this does not necessarily mean that they cannot decide what to eat, wear and do each day.

4.7 Reasonable Adjustments

A reasonable adjustment is a change that has been made to a service so that people with learning disabilities can use them like anyone else (Turner, 2011). However according to the Equality Act (2010) Adjustments only have to be made if it's **reasonable** to do so. What's a reasonable thing to ask for depends on things like:

- The level of/type of disability.
- How practicable the changes are.
- If the change you ask for would overcome the disadvantage you and other disabled people experience.
- The size of the organisation.
- How much money and resources are available.
- The costs of making the changes.
- If any changes have already been made.

Most reasonable adjustments can easily be accommodated and simply require staff to listen to the patient/carer – a small adjustment can make a big difference, the learning disability and/or autism team are available to advise.

5. Duties, Roles and Responsibilities

5.1 Trust Board of Directors

- (a) Overall responsibility for the quality of care that the Trust provides.
- (B) Review of annual report.

5.2 Chief Nurse

- (a) Responsible for the overall safe and supportive care of patients in UHBW including those with learning disabilities and/or autism.

5.3 Learning Disability and/or Autism Steering Group

- (a) Governance of the learning disability team work plan.

- (b) Work in partnership to protect and support the safe care of patients within UHBW.
- (c) Oversee the Learning Disability service provision, in line with 2018 Improvement Standards for NHS Trusts.
- (d) Ensure a safe system of flagging is in place to alert staff to learning disability and/or autism status.
- (e) Be responsible for ensuring learning disability/autism training opportunities are available for clinical staff at a level appropriate to their role and level of responsibility.
- (f) Maintain oversight and assurance of data provided to the Integrated Commissioning Board for learning disability/and or autism Commissioning standards at UHBW.
- (g) This group reports quarterly to the Safeguarding Steering Group chaired by the Chief Nurse.
- (h) Review all policies and documents relating to the provision of safe care to people with a learning disability and/or autism.

5.4 *Adult Strategic Lead - Learning Disabilities and/or Autism Services*

- (a) Professional management of Sirona Learning Disabilities Liaison Nurses.
- (b) Attendee at the Learning Disability Steering Group, and other internal meetings if required, supporting the delivery of service against the defined work plan.
- (c) Represent UHBW learning disability and/or autism services at national, regional and local strategic meetings.
- (d) Trust learning disability and/or autism lead for LeDeR.

5.5 *Sirona Learning Disabilities and/or Autism Specialist Liaison Nurse team*

- (a) Support adult patients with learning disabilities and/or autism, their carers and community professionals; ensuring this patient group has equal access to UHBW services; both elective and emergency and to have oversight of the patient journey.
- (b) Support, educate and validate the reasonable adjustments that clinical areas make to enable equal access to Trust services for adult patients with a known learning disability and/or autism including care audits.
- (c) Provide expert advice on assessing mental capacity, decision making and best interests.
- (d) Provide education and training for staff in communicating and caring for individuals with a learning disability and/or autism.

- (e) Ensure UHBW has comprehensive learning disability and/or autism intranet and external web pages for staff.
- (f) Via Sirona will attend external networks and undertake training opportunities.
- (g) In line with LeDeR carry out internal structured judgement reviews on people with a learning disability and/or autism who have deceased in UHBW.
- (h) Liaise with Sirona colleagues in local community learning disability teams.
- (i) Follow the SOP for placing learning disability and/or autism flags/alerts on electronic patient records, and maintain contemporaneous records.
- (j) Ensure availability and production of a range of easy read leaflets and other documentation, working collaboratively with Sirona staff at North Bristol Trust.
- (k) Specialist Band 7 will chair a local service user led hospital learning disability group, providing a mechanism for carers and service users to actively engage with the Trust, leading patient care developments and acting on feedback.
- (l) Contribute to a quarterly report reflecting service user involvement activity and innovation in learning disability and/or autism care.
- (m) Work alongside the children disability nurse and paediatric clinicians to support a smooth transition for children with a diagnoses of learning disability and/or autism into adult services.
- (n) Take responsibility for raising incidents following trust process and alerting senior staff.
- (o) To challenge poor practice and discuss immediately with senior staff/personnel.

5.6 *Children's' Disability Clinical Specialist*

- (a) Supports paediatric patients with lifelong physical, mental and sensory impairments, ensuring this patient group has equal access to services in UHBW.
- (b) Provide education and training in communicating and caring for children and parents/carers of children with lifelong physical, mental and sensory impairments and complex health needs.
- (c) Support transition from paediatric to appropriate adult services for children and young people with lifelong physical, mental and sensory impairments and complex health needs.

5.7 *Heads of Nursing / Midwifery*

- (a) Leadership for reviewing and delivering the learning disability and/or autism policy and associated documents.

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- (b) Provide a quarterly report to the learning disability and/or autism steering group on activity and compliance related to learning disability and/or autism patients within the division, including themes following mortality reviews and reported incidents.
- (c) Support data collection and audit within divisions.
- (d) Support the roll out of learning disability and/or autism specific training for all staff.
- (e) Support and promote the role of learning disability and/or autism champions within the division.

5.8 *Matrons*

- (a) Overall leadership for the delivery of reasonable adjustments for patients with learning disabilities at a local level.
- (b) Support ward sisters/charge nurses in the implementation of this policy.
- (c) Support wards to meet the needs of patients with a learning disability and/or autism where possible, through reasonable adjustments. Accepting that not all adjustments may be considered reasonable.
- (d) Ensure the dignity and respect for people with a learning disability and/or autism is upheld within clinical and non-clinical areas.

5.9 *Ward Sisters / Charge Nurses*

- (a) Day to day leadership for the delivery of reasonable adjustments for patients with a known learning disability and/or autism in their care.
- (b) Ensure staff within their area are current with their knowledge and training relating to care delivery and reasonable adjustments.
- (c) Monitoring implementation of this policy via audit and review.
- (d) Understand key themes from incidents and mortality reviews and take appropriate action in relation to patients with a learning disability and/or autism.
- (e) Enable staff to engage in the role of learning disability and/or autism champion.

5.10 *Registered and Unregistered Staff*

- (a) Recognition of patients with learning disabilities and/or autism; implementing reasonable adjustments to facilitate equal access to services.
- (b) Timely referral to specialist learning disabilities and/or autism team.
- (c) Delivery of excellent patient care leading to a positive patient experience.

- (d) Advocates for people with a learning disability and/or autism who struggle with communication or those without a voice.

5.11 Carers and Relatives

- (a) With consent or in best interest carers/relatives should be kept informed of changes in condition/observations and be offered explanations about the observation level and the reasons for that level.
- (b) Caring for someone in distress is not a process to which only professionals can contribute. Carers with an awareness of the patient's risks can, at times, help and may, on occasions, be more appropriate than the professional.
- (c) Informal carers are not paid by the Trust to assist with care. Formal carers already provided in the patients care placements or supported living may wish to support their client whilst an inpatient and invoice the Trust for services provided. This will need to be discussed prior to the arrangement with the Ward Sister, Matron and authorised by the Deputy Head of Nursing.

5.12 Medical professionals

- (a) Have an understanding of the policy and their role.
- (b) When assessing and treating patients with a learning disability and/or autism, consider which reasonable adjustments are required to support and encourage patient engagement; seek advice when needed from the learning disability and/or autism team.
- (c) Demonstrate their knowledge of and work within the Mental Capacity Act (2005) and support the best interest decision making process.
- (d) Identify the risks of diagnostic overshadowing and treat the patient in a holistic manner, drawing on the expertise of the specialist learning disability and/or autism liaison nurses.

6. Policy Statement and Provisions

6.1 Risk Governance and Assurance

UHBW divisions undertakes monthly data collection audits to provide a narrative and record of incidence of patients with a known learning disability attending the Trust, the report will include:

- Themes from reported patient safety incidents including restrictive interventions and action taken.
- Safeguarding concerns raised.
- Learning from deaths and actions taken.

The learning disability and/or autism steering group reports to the quarterly safeguarding steering group, this report will include developments within the learning disability and/or autism service, divisional updates and progress with the work plan.

The Bristol Royal Hospital for Children (BRHC) does not have a specific learning disability and/or autism children's nurse although it has the support of a children's disability specialist nurse (CDSN) based within the Hospital. The CDSN ensures that the care of the disabled child is seamless. In ensuring this takes place for young adults with a learning disability and/or autism spectrum disorder or disability, the Trust is committed to the development of transition planning nursing; that all young people and children have a happy and healthy childhood, with the best possible outcomes, is a key priority for Bristol. This includes planning for young people with additional needs and their families. Planning for the future is particularly important, to develop and support aspiration and quality of life.

The CDSN is working in partnership with the Bristol Transitions Strategy and Protocol which reflects the outcome of extensive multi-agency work to ensure that transition from children's to adult provision (whether in education, health, social care or universal services) is planned, positive and personalised.

6.2 Governance of Clinical Alerts

Flagging systems –Clinical Alerts. Clinical alerts are in place to flag all patients with a known learning disability and/or autism. These specific clinical alerts are managed and responded to by the learning disabilities and/or autism team. Once a patient is placed on the clinical alert system, the system will inform:

- (a) When a patient has a planned admission.
- (b) Following admission to all departments within UHBW.
- (c) Patient transfers within the hospital.
- (d) Patient discharge/death.

Flagging systems-Care Flow EPR. The electronic patient record allows quick access to additional patient information and linked applications. Any reasonable adjustments identified by the specialist team can be found here for inpatient admission or outpatient attendances. They can contribute to assessment and ensure reasonable adjustments are made when and where required in order to meet presenting needs.

7. References

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