



Royal Cornwall Hospitals
NHS Trust

Adults and Children with Autism Spectrum Disorder Policy

V3.0

November 2023

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Data Protection Act 2018 (UK General Data Protection Regulation – GDPR) Legislation.

The Trust has a duty under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 to ensure that there is a valid legal basis to process personal and sensitive data. The legal basis for processing must be identified and documented before the processing begins. In many cases we may need consent; this must be explicit, informed, and documented. We cannot rely on opt out, it must be opt in.

Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 is applicable to all staff; this includes those working as contractors and providers of services.

For more information about your obligations under the Data Protection Act 2018 and UK General Data Protection Regulations 2016/679 please see the Information Use Framework Policy or contact the Information Governance Team.

Royal Cornwall Hospital Trust rch-tr.infogov@nhs.net

1. Introduction

- 1.1. This Policy title uses the overarching term autism spectrum disorder (ASD). This term is used throughout to describe autism, autism spectrum disorder, autism spectrum condition and, although no longer formally diagnosed, Aspergers syndrome.
- 1.2. It is recognised that autistic people use a wide range of language to describe their identity. Some may see autism as part of them and prefer to be described as autistic or on the autism spectrum, opposed to someone with autism (NHS England, 2023). For inclusivity this Policy uses a combination of terminology.
- 1.3. It is acknowledged that some individuals will have a formally documented diagnosis of Autism and others may self-identify.
- 1.4. The term 'spectrum' is used as the characteristics of the condition vary from one person to another. Although all people with autism share specific difficulties, the way it affects them can vary greatly. This variation can also depend on their current health status, their present environment, their developmental stage, and other co-existing conditions for example: ADHD, Mental Health concerns, Learning Disabilities or Epilepsy (NHS, 2022).
- 1.5. 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. Autism affects around 1:100 people, and there are around 700,000 autistic adults and children in the UK (National Autistic Society, 2023).
- 1.6. The shared difficulties experienced by autistic people can include:
 - **Social Communication, Social Interaction and Social Imagination:**
Difficulty interpreting language, gestures, or tone. Difficulty with social relationships, appearing detached, distant, or intensely towards others. Difficulty with interpersonal play and imagination.
 - **Repetitive or restrictive behaviors.**
 - **Sensory differences, whether hyper or hyposensitive to sound, touch, pain, light, taste, touch or other sensory stimuli:**
These differences can cause discomfort or pain and anxiety for the person.
 - **Anxiety, and Shutdown or meltdown behaviours.**
 - **Highly focused interests or hobbies.**(National Autistic Society, 2023)
- 1.7. The following documents identify that a significant proportion of adults with autism across the whole spectrum experience social and economic exclusion:
 - [Autism Act \(2009\)](#)
 - [Vision to Reality Strategy 2023-2026, National Autistic Society](#)

- [Autism - The Nice Guideline on the Management and Support of Children and Young People on the Autism Spectrum](#)

The National Institute for Health and Care Excellence (NICE, 2021) describe autism as '*Frequently overlooked by Health, Education and Social Care Professionals, which in turn creates barriers to accessing the support and services needed*'.

[NICE guidelines](#) offer best practice advice on the person-centered care of adults with autism. They highlight 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 lack capacity, decisions are made in the individual's best interests according to the statutory requirements set out through the [Mental Capacity Act \(2005\)](#). This Protocol sets out how the Royal Cornwall Hospitals NHS Trust will meet the best practice guidelines to ensure a safe and responsive service for autistic people.

1.8. This version supersedes any previous versions of this document.

2. Purpose of this Policy/Procedure

2.1. Autistic people have the right to the same level of health care as that provided to the general population. This care should be flexible and responsive, and any diagnosis or treatment must take account of specific needs associated with the person's needs relevant to autism.

2.2. This Protocol has been subject to an Equalities Impact Assessment Screening and all aspects will enhance equality. To ensure adherence to these principles the main areas of focus will be:

- To enable staff at the acute Trust to develop a better understanding of autism and to equip them to deal more effectively with the needs of each individual.
- To clarify for support staff attending the hospital with an autistic person, their supporting/caring role and the boundaries between their caring role and the nursing role of the hospital staff.
- To support patients, parents, and carers in implementing the RCHT 'Autism Quick Guide to me'.
- To provide an opportunity for hospital staff and the dedicated Liaison Nurse to work together to develop: effective communication, training and education awareness and accessible information.

3. Scope

This protocol applies to all staff employed within Royal Cornwall Hospitals Trust who have responsibility for the care of patients, or provide a service, including those who are autistic.

4. Definitions / Glossary

Autism - a lifelong developmental disability that affects:

- How a person communicates with and relates to other people.
- How they make sense of the world around them.
- It is a spectrum condition, which means that people with Autism share certain difficulties; their condition will affect them in different ways.
- Individuals may have restricted and repetitive behaviours, activities, or interests.
- Individuals may experience sensory sensitivity and/or sensory processing disorders.

Note: The [National Autistic Society](#)

5. Ownership and Responsibilities

5.1. Role of the Chief Executive and wider Trust Board

The Chief Executive and wider Trust Board are responsible for:

- Ensuring the Trust meets requirements set out by statutory and regulatory authorities such as the Department of Health, Commissioners and the Care Quality Commission.
- Ensuring that clinical staff are aware of this Policy and adhere to its requirements.
- Ensuring that appropriate resources exist to meet the requirements of this Policy.

5.2. Role of the Executive Directors:

Executive Directors are responsible for:

- Ensuring that all operational managers in their area are aware of this Policy, understand its requirements and support its implementation.

5.3. Role of the Associate Medical Director/Consultants

The Associate Medical Director and Consultants are responsible for:

- Ensuring legal frameworks and procedures detailed in this Policy are understood and adhered to by medical staff.

5.4. Role of the Ward/Unit Managers

Ward/Unit Managers are responsible for:

- Implementing this Policy.

- Ensuring that relevant assessment tools are readily available to allow staff to carry out the duties prescribed in this Policy.

5.5. Role of the Members of Clinical Teams

Clinical team members have responsibility for:

- Complying with the requirements of this and associated policies and have a legal duty to adhere to the Act and Code when working with, or caring for, adults who may lack capacity to make decisions for themselves.

5.6. Role of the Quality, Safety and Compliance Team

The Quality, Safety and Compliance Team are responsible for:

- Informing the Care Quality Commission (CQC) of all DoLS (Deprivation of Liberty Safeguards) applications and outcomes - this is a statutory requirement.

5.7. Role of the RCHT Safeguarding Operational Group (SOG)

The Safeguarding Operational Group is responsible for:

- Disseminating significant information and developments relating to the Adult Safeguarding local and national agendas.
- Supporting and identifying ongoing staff training needs and taking forward proposals for training through senior management channels.

5.8. Role of Individual Staff (including volunteers)

All staff members (including volunteers) are responsible for:

- Being aware of what autism means, how individuals should be treated and from where they can find more information and help.

5.9. Role of Clinical Staff

- Clinical staff who may be involved in the assessment, diagnosis, treatment, or care of autistic patients are responsible for:
- Identifying patients and adapting their approach accordingly; care and treatment plans must be drawn up with autism in mind so that reasonable adjustments are planned and delivered.
- Knowing how to get help and advice and do so as necessary; staff have been advised to contact the Acute Liaison Nurse for further information on 'easy read' patient information.
- Acting as the patients' advocate ensuring they are given information about their condition and/or treatment in a way that they can understand to make decisions within any limits of their capacity.

Note: It is important that clinical staff acknowledge that the individual or their family members/carers understand their needs best, and work in partnership with them to ensure that the communication needs of the individual are met.

6. Standards and Practice

6.1. The 'Autism Quick Guide to me'

The Royal Cornwall Hospital is dedicated to the development and introduction of the 'Autism Quick Guide to me'. This is a patient held record that accompanies the patient throughout their journey in hospital. It provides key information for staff such as communication needs, social needs, and behavioural patterns. This document helps patients and carers highlight specific support needs before and during admission. Clinical staff are then able to better assess, plan, manage and evaluate care and treatment using a much more person-centred approach.

6.2. The Hospital Communication Book

6.2.1. A hard copy of the Hospital Communication Book has been made available to all staff on each ward, clinic & department. This is an excellent resource that contains useful information and advice and a range of communication techniques and strategies such as signs and symbols on how to communicate effectively with people who have difficulties with communication. Please see The Clear Communication People resource for extra information.

6.2.2. Accessible information is available when required about procedures, services, and treatment. The Acute Liaison Team also have electronic tablets that are used on an individual basis to aid communication with a variety of applications available. Ensuring that equal and effective individualised communication is achieved to support positive health outcomes.

6.2.3. Individual reasonable adjustments are made when required as mandated by the Equality Act (2010). Some examples of these are below:

- [National Autistic Society](#)
- **Appointments**
 - Try to give the patient the first or last appointment of the day. Autistic people may find waiting for an appointment extremely stressful.
 - Waiting in busy hospital corridors may increase anxiety/stress levels of an already anxious child or adult.
 - If possible, find a small side room the individual/family can wait in.
 - Alternatively, they may prefer to wait outside or in the car and a

member of staff should be identified to collect them when the health professional is ready. If the appointment is likely to be delayed, the individual/family may wish to leave the building completely and return at a later agreed time.

- **Medical Procedures**

Always explain what you are going to do before starting any procedure or examination. If possible, show a picture of what is going to happen or use a demonstration model (if appropriate) to explain what you are going to do.

- **Your Language**

- Use clear simple language with short sentences.
- People may take what you say literally. If you say "It will only hurt for a minute" they may expect the pain to have gone within one minute.
- Make your language concrete and avoid using idioms, irony, metaphors, and words with double meanings, e.g. 'It's raining cats and dogs out there' - this could cause the patient to look outside for cats and dogs.
- Give direct requests: 'please stand up'. If you say, 'can you stand up?' this may result in the person staying seated or the answer 'yes', as the person may not understand you are asking them to do something.
- Check that they have understood what you have said - some people may speak clearly but can lack full understanding.
- Avoid using body language, gestures, or facial expressions without verbal instructions as these may not be understood.
- Ask for the information you need. Vital information may not be volunteered without being asked directly.

- **Physical Examinations**

- These may prove very stressful to the patient, and it is essential to warn them before touching them.
- Explain what you are doing and why.
- Enlist the parent/carers help wherever possible, especially if the patient is non-verbal or uses an alternative communication method or aid.

- **Response By Patient**
 - Lack of eye contact does not necessarily mean they are not listening to what you are saying, or that they are not in distress.
 - Allow the patient extra time to process what you have said.
 - Don't assume that a non-verbal patient cannot understand what you are saying.
 - Some people may find it difficult to understand another person's perspective. They may not understand what you intend to do but may expect you to know what they are thinking.
 - Some people may not understand personal space. They may invade your personal space or need more personal space than another person.
- **Lights**
 - Some autistic people are sensitive to light and can find difficulties with the flashing of fluorescent lights.
 - Pen lights can trigger seizures in susceptible individuals. Seizures occur in 20-30% of autistic people.
- **Sensory Overload**
 - It is easy for someone with autism to be overcome by sensory stimuli. Emergency lights and machines emit high-pitched sounds which can be uncomfortable or cause physical pain.
 - Whereas some might withdraw (e.g. put their fingers in their ears, close their eyes) others 'stim'. This means to make motions such as flapping hands, rocking or flicking fingers to stimulate sensation or to deal with stress. This kind of behaviour may also be calming to the individual, or aid balance and posture, so do not try and stop it unless essential to do so for their safety.
- **Pain**
 - Autistic people can have different pain thresholds. Even if the person does not appear to be in pain, they may be experiencing significant pain or discomfort.
 - They may show an unusual response to pain that could include laughter, humming, singing or removal of clothing.
 - Agitation and behaviour patterns may be the only sign that the child or adult is in pain.

- **Injections/blood tests:**
 - If the patient needs an injection or blood test try and divert their attention elsewhere as before, the use of pictures or a demonstration model may help.
 - Some people can be either hypo or hypersensitive to pain. Some may feel pain acutely and be very distressed whereas others may not appear to react at all.
 - It is advisable to assume that the patient will feel the pain and use a local anesthetic cream such as EMLA cream to numb the site of injection.
- **Emergency Department (ED)**
 - ED is a stressful environment for most people, but for the person with an autism it can be overwhelming. Not only is it a strange place, and at times chaotic, the sensory experience of bright lights, beeping monitors, and other equipment, can cause overwhelm and 'meltdown' or withdrawal.
 - A meltdown occurs when someone becomes over stimulated, for example by noise, or too much information, or due to anxiety. This leads to a state of not being able to cope with any further incoming information and possible behavioural outbursts or withdrawal.
 - Allow the parent or carer to take control, as they will know the best way to calm the patient down. The patient may exhibit challenging behaviour and parents/carers should be allowed to calm the patient down.
 - Sometimes doctors and nursing staff ask relatives/carers to leave the room whilst giving emergency treatment. It may be helpful to allow them to stay if possible and safe to do so. This can help reassure the patient and will also allow the relatives/carers to give valuable information about the patient and their behaviour, if appropriate.
 - Inform the triage nurse that the patient has an autistic spectrum condition so that they can be given a higher priority than would be normal. This is to minimise the time the patient must wait and is classed as a reasonable adjustment.
 - Allow the patient and carers to use the relatives room if available.
 - Try to limit the number of staff caring for the patient. Predictability through continuity may help them understand what is happening and identify the roles of care providers to aid clarity.
 - Allocate a key person to the patient wherever possible.

6.3. Training and Education

- 6.3.1. The Acute Liaison Nurses provide training for clinical staff on their Induction and mandatory updates, which aim to improve the knowledge, skills and awareness of all staff who are involved in or who contribute to the patient pathway for people with Autism. The training is coordinated by the Learning and Development Department and is aimed at all staff across the Trust.
- 6.3.2. The Safeguarding Team also has a number of Link Staff who are the link professional for their ward/department. The link professionals have an extra level of training (level 2) and are provided with more in depth information on how to best support patients with Autism. They are the link person to provide their ward/department with new and up dated information are invited to relative training courses.

6.4. Partnership Working

Multi-agency and multi-disciplinary partnership working is essential to ensuring positive health outcomes for autistic people. Working together with other health providers such as the Community Teams 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 things being missed.

6.5. Flagging Alert System

Continue to add to the Patient Administration System a flag to highlight when a patient has Autism. This sends an automatic alert to the Acute Liaison Nurse team when the patient is admitted to the hospital.

6.6. Complaints

Service users and/or carers should be supported to use the hospital's complaints procedure if there are concerns that cannot be addressed by ward or clinic staff. The Patient Advice and Liaison Service (PALS) can assist with addressing concerns and issues on behalf of service users and carers. An easy read leaflet has been produced providing information on how to comment or complain.

7. Dissemination and Implementation

- 7.1. This Policy is to be implemented and disseminated through the organisation immediately following ratification and will be published on the Trusts Document Library via the Intranet.
- 7.2. The Policy will be launched via the Updated Policies, Guidelines, Procedures and Web Documents Communications mail out.
- 7.3. The Policy will be available via the Documents Library on the Internet.

- 7.4. This Policy will be shared with the Community Cornwall Autism Partnership Group and leadership groups for people with ASC.
- 7.5. Provision of Mandatory Adult Safeguarding training, including the Mental Capacity Act (2005), will be delivered by the Learning and Development Department as outlined in the Mandatory and Statutory Training Policy. Reference to relevant sections from this Policy will be utilised at all RCHT Level 1 and 2 Adult Safeguarding Mandatory training.

8. Monitoring compliance and effectiveness

| Information Category | Detail of process and methodology for monitoring compliance |
|---|---|
| Element to be monitored | Standards of Practice by undertaking an audit. |
| Lead | The Acute Liaison Manager will lead on this. |
| Tool | An Audit will be used - by selecting patient notes and making contact to ask if the standards of practice were followed. |
| Frequency | Annual Learning Disability and Autism report completed annually. |
| Reporting arrangements | The completed audit report will be discussed at the RCHT Safeguarding Operational Group (SOG) and will be forwarded to the CIOB ICB Clinical Commissioning Manager. |
| Acting on recommendations and Lead(s) | Where the report indicates sub optimal performance the Chair of SOG will nominate a group member to produce an action plan. |
| Change in practice and lessons to be shared | The SOG will be responsible for monitoring progress and will undertake subsequent recommendations and further action planning for all deficiencies identified within agreed timeframes. |

9. Updating and Review

This process is managed via the Document Library. A review will be undertaken in three years unless best practice dictates otherwise.

10. Equality and Diversity

10.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the [Equality Diversity And Inclusion Policy](#) or the [Equality and Diversity website](#).

10.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.

Appendix 1. Governance Information

| Information Category | Detailed Information |
|--|---|
| Document Title: | Children and Adults with Autism Spectrum Conditions V3.0 |
| This document replaces (exact title of previous version): | Children and Adults with Autism Spectrum Conditions V2.0 |
| Date Issued / Approved: | November 2023 |
| Date Valid From: | November 2023 |
| Date Valid To: | November 2026 |
| Author / Owner: | Jane Rees, Acute Liaison Nurse and Manager of the Learning Disabilities and Autism Team |
| Contact details: | 01872 255741 |
| Brief summary of contents: | Description of Autism and how health professional staff needs to support patients with the condition. |
| Suggested Keywords: | Autism, Safeguarding, Asperger's syndrome, learning disability, ASD, LD. |
| Target Audience: | RCHT: Yes CFT: No CIOS ICB: No |
| Executive Director responsible for Policy: | Deputy CEO and Chief Nurse Officer |
| Approval route for consultation and ratification: | RCHT Safeguarding Operational Group (SOG) |
| Manager confirming approval processes: | Zoe Cooper |
| Name of Governance Lead confirming consultation and ratification: | Zoe Cooper |

| Information Category | Detailed Information |
|---|--|
| Links to key external standards: | Autism Act (2009) Autism - The Nice Guideline on the Management and Support of Children and Young People on the Autism Spectrum Autism Spectrum disorder in Adults: Diagnosis and management Vision to Reality Strategy 2023-2026 Making information and the words we use accessible (NHS England, 2023) |
| Related Documents: | Autism Act (2009) Equality Act (2010) Mental Capacity Act (2005) |
| Training Need Identified: | Yes - RCHT is responsible for ensuring all clinical staff are offered training with regards to the key aspects of supporting children and adults with autism spectrum disorders. |
| Publication Location (refer to Policy on Policies – Approvals and Ratification): | Internet and Intranet |
| Document Library Folder/Sub Folder: | Clinical / Safeguarding Services / Learning Disabilities & Autism, Acute Liaison |

Version Control Table

| Date | Version Number | Summary of Changes | Changes Made by |
|----------|----------------|------------------------------------|---|
| May 2014 | V1.0 | Initial version | Daniella Rubio-Mayer Acute Liaison Nurse Manager |
| Jul 2017 | V1.1 | Review – minor amendments made | Lerryn Hogg - Manager Mental Health, LD and Autism |
| Jul 2020 | V2.0 | Change of name and 3 yearly review | Jane Rees, Acute Liaison Nurse and Manager of the Learning Disabilities and Autism Team |

| Date | Version Number | Summary of Changes | Changes Made by |
|----------|----------------|---|---|
| Nov 2023 | V3.0 | Full Update Language use review References reviewed and updated | Jane Rees, Acute Liaison Nurse and Manager of the Learning Disabilities and Autism Team |

All or part of this document can be released under the Freedom of Information Act 2000

All Policies, Strategies and Operating Procedures, including Business Plans, are to be kept for the lifetime of the organisation plus 6 years.

This document is only valid on the day of printing.

Controlled Document

This document has been created following the Royal Cornwall Hospitals NHS Trust [The Policy on Policies \(Development and Management of Knowledge Procedural and Web Documents Policy\)](#). It should not be altered in any way without the express permission of the author or their Line Manager.

Appendix 2. Equality Impact Assessment

Section 1: Equality Impact Assessment (EIA) Form

The EIA process allows the Trust to identify where a policy or service may have a negative impact on an individual or particular group of people.

For guidance please refer to the Equality Impact Assessment Policy (available from the document library) or contact the Equality, Diversity, and Inclusion Team
rcht.inclusion@nhs.net

| Information Category | Detailed Information |
|---|---|
| Name of the strategy / policy / proposal / service function to be assessed: | Children and Adults with Autism Spectrum Conditions V3.0 |
| Department and Service Area: | Corporate / Safeguarding Services / Learning Disabilities and Autism, Acute Liaison |
| Is this a new or existing document? | Existing |
| Name of individual completing EIA (Should be completed by an individual with a good understanding of the Service/Policy): | Jane Rees, Acute Liaison Nurse and Manager of the Learning Disabilities and Autism Team |
| Contact details: | 01872 255741 |

| Information Category | Detailed Information |
|---|---|
| 1. Policy Aim - Who is the Policy aimed at? (The Policy is the Strategy, Policy, Proposal or Service Change to be assessed) | To enable staff at the acute Trust to develop a better understanding of autistic people and to equip them to deal more effectively with the particular needs of each individual. |
| 2. Policy Objectives | To enable staff at the acute Trust to develop a better understanding of people with autism and to equip them to deal more effectively with the particular needs of each individual. |
| 3. Policy Intended Outcomes | That all staff have improved understanding of people with Autism and are able to apply that understanding when providing or supporting their care and treatment. |
| 4. How will you measure each outcome? | Annual audit of this Policy. |
| 5. Who is intended to benefit from the policy? | All staff. |

| Information Category | Detailed Information |
|--|--|
| 6a. Who did you consult with? (Please select Yes or No for each category) | <ul style="list-style-type: none"> • Workforce: Yes • Patients/ visitors: No • Local groups/ system partners: No • External organisations: No • Other: No |
| 6b. Please list the individuals/groups who have been consulted about this policy. | Please record specific names of individuals/ groups: Learning Disabilities and Autism, Acute Liaison Team. RCHT Safeguarding Operational Group (SOG). |
| 6c. What was the outcome of the consultation? | Approved. |
| 6d. Have you used any of the following to assist your assessment? | National or local statistics, audits, activity reports, process maps, complaints, staff or patient surveys: No. |

7. The Impact

Following consultation with key groups, has a negative impact been identified for any protected characteristic? Please note that a rationale is required for each one.

Where a negative impact is identified without rationale, the key groups will need to be consulted again.

| Protected Characteristic | (Yes or No) | Rationale |
|---|-------------|--|
| Age | No | This policy strengthens and clarifies the Trust's expectations for the care and treatment of people with Autism. It aims to ensure that patients who have autism are empowered and protected. |
| Sex (male or female) | No | As above |
| Gender reassignment (Transgender, non-binary, gender fluid etc.) | No | As above |
| Race | No | As above |
| Disability (e.g. physical or cognitive impairment, mental health, long term conditions etc.) | No | As above |

| Protected Characteristic | (Yes or No) | Rationale |
|---|-------------|-----------|
| Religion or belief | No | As above |
| Marriage and civil partnership | No | As above |
| Pregnancy and maternity | No | As above |
| Sexual orientation (e.g. gay, straight, bisexual, lesbian etc.) | No | As above |

A robust rationale must be in place for all protected characteristics. If a negative impact has been identified, please complete section 2. If no negative impact has been identified and if this is not a major service change, you can end the assessment here.

I am confident that section 2 of this EIA does not need completing as there are no highlighted risks of negative impact occurring because of this policy.

Name of person confirming result of initial impact assessment: Jane Rees

If a negative impact has been identified above OR this is a major service change, you will need to complete section 2 of the EIA form available here:
[Section 2. Full Equality Analysis](#)