# Joint Trust Guideline for the Management of Children and Young people coming to hospital for inpatient and outpatient treatment and/or Investigation who have Social Communication Disorders (SCD) (Including Autism Spectrum Condition (ASC))

## Document Control:

| | | | |
|---|---|---|---|
| **For Use In:** | James Paget University Hospital NHS Foundation Trust (JPUH) and Norfolk and Norwich University Hospital NHS Foundation Trust (NNUH) | | |
| | The Children/young people's department and all clinical areas providing treatment/investigation for children/young people and young people. | | |
| **Search Keywords** | Social Communication Disorder, SCD, Autistic Spectrum Condition, ASC, Autism, children, young people | | |
| **Document Author:** | Learning Disability and Autism matron | | |
| **Document Owner:** | Learning Disability and Autism matron /Complex Health Hub | | |
| **Approved By:** | Clinical Guidelines Assessment Panel (CGAP) | | |
| **Ratified By:** | The Clinical Safety and Effectiveness Sub-Board (CSESB) | | |
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## Version History:

| Version | Date | Author | Reason/Change |
|---|---|---|---|
| V1.0 | December 2011 | Sister, Buxton Ward | To originate document |
| V2.0 | January 2015 | Sister, Buxton Ward | Amended to include JPUH |
| V3.0 | March 2023 | Learning Disability Nurse Matron | Document reviewed and transferred to new Trust docs template |

## Previous Titles for this Document:

| Previous Title/Amalgamated Titles | Date Revised |
|---|---|
| None | Not applicable |

Note which Trust, where applicable.

## Distribution Control

Printed copies of this document should be considered out of date. The most up to date version is available from the Trust Intranet.

## Consultation

The following were consulted during the development of this document:
Emma Chapman, Senior Matron Children/ Young peoples services
Barbie Alden, Paediatric Registrar, James Paget Hospital, Fiona Springall & Lydia Smith, Learning Disability & Autism team NNUH

The authors listed above on behalf of a guideline development group, which has agreed the final content, drafted the guideline. During its development it has been circulated for comment to: Paediatricians and staff in clinical areas where children/young people are seen with in the Trust.

The final version incorporates their comments and has been endorsed by the Clinical Guidelines Assessment Panel (CGAP).

## Monitoring and Review of Procedural Document

The document owner is responsible for monitoring and reviewing the effectiveness of this Procedural Document. This review is continuous however as a minimum will be achieved at the point this procedural document requires a review e.g. changes in legislation, findings from incidents or document expiry.

## Relationship of this document to other procedural documents

This document is a clinical guideline applicable to, Acute Collaborative; please refer to local Trust's procedural documents for further guidance, as noted in Section 5.

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**Quick reference**

## CHILDREN/YOUNG PEOPLE COMING TO HOSPITAL FOR OUTPATIENT APPOINTMENT / INVESTIGATION

# Joint Trust Guideline for the Management of Children and Young people coming to hospital for inpatient and outpatient treatment ad/or Investigation who have Social Communication Disorders (SCD) (Including Autism Spectrum Condition (ASC))

## 1. Introduction

Children/young people who have Social Communication Disorders (SCD) may have significant difficulty understanding the need for and process of a hospital visit, sometimes resulting in behaviour which could be challenging to support. Unusual and challenging behaviours are often present and may be displayed as:

- extreme reactions to minor changes,
- sensitivities to particular sounds, sights or textures
- compulsive routines
- repetitive motor behaviours

### 1.1. Rationale

This guideline has been approved by the Trust's Clinical Guidelines Assessment Panel as an aid to the diagnosis and management of relevant patients and clinical circumstances. Not every patient or situation fits neatly into a standard guideline scenario and the guideline must be interpreted and applied in practice in the light of prevailing clinical circumstances, the diagnostic and treatment options available and the professional judgement, knowledge and expertise of relevant clinicians. It is advised that the rationale for any departure from relevant guidance should be documented in the patient's case notes.

The Trust's guidelines are made publicly available as part of the collective endeavour to continuously improve the quality of healthcare through sharing medical experience and knowledge. The Trust accepts no responsibility for any misunderstanding or misapplication of this document.

While many children/young people/young people with Social Communication Disorders (SCD) have no other medical problems, SCD, in particular Autistic Spectrum Condition (ASC), are well recognised to be associated with increased frequency of a number of additional medical and psychiatric conditions. These include Gastrointestinal disorders (constipation, abdominal pain, gastroesophageal reflux), epilepsy, feeding and sleep disorders, anxiety and OCD (obsessive compulsive disorder). SCD can also be a feature in children/young people/young people with complex medical and genetic disorders. With regard to this background, it can be expected that a significant number of children/young people/young people attending in- and outpatient appointments will have a comorbid diagnosis of SCD.

NICE guidance and recommendations from the National Autistic Society advise that healthcare professionals and hospitals should take into account the physical environment in which Autistic children/young people and are cared for and seek to minimise any negative impact. Furthermore, the Autism Act (2009) and Equality Act

(2010) underpin the requirement for reasonable adjustments to be made to support Autistic people when attending hospital.

Alternative forms of communication and sensory sensitivities could make a hospital visit a challenge for the child/young person, family and health professional. The implementation of some or all of the suggested practical measures may assist in making the experience a positive one reducing the stress felt by the child/young person and family.

### 1.2. Objective

The objective of the Clinical Guidelines is to:

- Inform all staff employed by the Trust who come into contact with Children/young people/young people with social communication disorders (including children and young people with autism) that these children/young people/ young people with autism may have additional communication requirements and needs to ensure their hospital visit is made as stress free for the child/young people/ young people with autism and carer as possible.
- To provide information for staff employed by the Trust as to some of the actions which could be taken to reduce any potential problems encountered by these children/young people/young people and their families when coming to hospital
- To ensure each child/young person is treated as an individual and is cared for with sensitivity, whilst working in partnership with the family.

### 1.3. Scope

This document will be relevant to all healthcare staff who may support autistic children and young people, or those children and young people with social communication needs.

### 1.4. Glossary

The following terms and abbreviations have been used within this document:

| Term | Definition |
|---|---|
| SCD | Social Communication Disorders |
| ASC | Autism Spectrum Condition |
| OPA | Outpatient appointments |
| OCD | Obsessive compulsive disorder |
| CGAP | Clinical guidelines and approval panel |
| PGD | Patient group directions |
| PALS | Patient advice liaison service |

## 2. Responsibilities

**Healthcare staff** – have a responsibility to act within the recommendations of the Equality Act 2010 and the Autism Act 2009. Reasonable adjustments should be made to healthcare provision in line with these acts and in accordance with individual patient need

**Learning Disability & Autism Team** – have a responsibility to provide specialist advice and recommendations to augment healthcare provision to children and young people with autism or social communication needs. The team has a responsibility to provide oversight of the care provided to this patient group (through review and audit) and to make adjustments to overall care provision and organisation of care accordingly.

## 3. Policy Principles

Refer to algorithms on page 2, 3 and 4.

For further information please refer to the Trusts Learning Disabilities Pack and the clinical area Link Nurse for Learning Disabilities. Norfolk and Norwich University Hospital NHSFT also has a policy for the care and management of children, young people and adults with a learning disability and/or Autism available on trust docs, and a learning disability specialist nursing team who are contactable for advice and support.

The following are some core areas which may cause children/young people distress when coming into hospital.

### 3.1. Social Communication:

Many children/young people have considerable difficulty in communicating with others. This applies not only to those children/young people who have limited verbal ability but also those children/young people and young people who can use speech but may fail to understand many of the subtleties of social communication (see later).

### 3.2. Social Interaction:

Children/young people and young people who have social communication disorders may find it difficult to respond in a manner typically expected of their peers. It is important to remember that ‘typical’ communication is indicative only of socially preferred norms, and that all forms of communication are valid and meaningful.

### 3.3. Change of routine or environment:

Many children/young people can find entering a new environment overwhelming and very stressful. This should be considered when assessing any individual in an environment new to them, and all reasonable efforts should be made to adjust the environment to more accurately meet their needs.

### 3.4. Unusual sensitivity to sensory stimuli:

Some young people with social communication disorders can find sounds, lights, smells and textures overwhelming. Adjustments should be made to accommodate these sensory needs wherever possible, for example by allowing children to wear their own clothes rather than hospital clothing.

#### 3.4.1. Appointments

- Waiting in hospital outpatient areas can increase the stress levels of an already anxious child/young person.
- Where possible identify children/young people with SCD/ASD during the clinic referral triage process and consider liaising with the family prior to allocating an appointment if medical records suggest attending clinic could be particularly challenging or stressful.
- Try to give patients with ASC/SCD the first or last appointment of the day and/or consider allocating double clinic slots to ensure enough time is available to provide the required, appropriately adjusted care.
- Ensure the consultant/healthcare professional in charge of the clinic is aware of the child's/young person's additional needs, and that they are waiting to be seen, particularly if a clinic is overrunning, in case alternative provision is possible.
- If possible find a side room or quiet area where they can wait. However, some children/young people may find this claustrophobic and each child's/young person's needs should be considered individually. The child/young person themselves, or their parent/carer would be able to help make this decision.
- The family may prefer to wait outside or in their car and a member of staff should be identified to collect them when appropriate. If the appointment is likely to be delayed the family may wish to leave and return at a later agreed time.

#### 3.4.2. Communication

- Children/young people with SCD have the same rights as all other children/young people to have their feelings and wishes taken into account and wherever possible to be involved in shared decision making. Achieving this will require good communication skills with both the child/young person and carers.
- Where possible encourage the child's/young person's

carers to try to prepare the child/young person for likely events and procedures in advance i.e. through pre-planned introductory visits to hospital and/or use of social stories.

- Consider gathering additional information about the child/young person using documents such as a health passport to ensure all needs are understood and met. Patients may wish to use the hospital passport created by the national Autistic Society (free to download) www.autism.org.uk/about/health/hospital-passport.aspx
- Always explain what you are going to do and what the child/young person can expect before starting any procedure or examination.
- Use clear simple, direct language with short sentences..
- Direct requests e.g. “Please stand up” rather than “can you stand up” may be more supportive to a child/young person
- Ask for the information you need using clear, unambiguous enquiries.
- If possible show a picture to aid explanation.
- Allow extra time for the child/young person to process what you have said
- Check (depending on their age) that they have understood what you have said.
- Do not assume that a non-verbal patient cannot understand what you have said.

### 3.4.3. Physical Examination

Although parents / carers will have given consent to physical examination it is essential to explain simply to the child/young person what you are planning to do and why.

Despite this warning the experience may still be stressful.

### 3.4.4. Sensory Stimulation

**Lights**

- Some people with ASC are extremely sensitive to light and can discern the flashing of fluorescent lights.
- Pen lights can trigger seizures in susceptible individuals. Seizures can occur in 20-30% of people with ASC.

**Sensory Overload**

- It is possible some individuals with ASC may feel overloaded by sensory information. Emergency lights and machines, general hustle and bustle and unfamiliar sounds can be difficult to process to the person with ASC.

### 3.4.5. Pain

- Healthcare professionals can miss pain expression in children and young people with autism or SCD, and should familiarise themselves with the person's methods of pain expression
- Atypical pain expression might include, for example, laughter, humming, singing or removal of clothing.
- Always consider non-verbal cues, such as a change in behavioural presentation, as a possible form of pain expression.

### 3.4.6. Injections and blood tests

- Try to minimise the length of time the child/young person is waiting before any invasive procedure/treatment. The hospital environment is likely to be stressful and the more stressed the child/young person is, the more difficult it will be to safely carry out the procedure. Consider environmental adjustments as listed above (under Appointments).
- Try and divert the child's/young person's attention elsewhere (play therapists should be used if available).
- Using pictures or social stories is a good idea for some children, to help them process what is going to happen.
- Using a doll to demonstrate may also be helpful.
- Use Emla or Ametop cream as per Patient Group Directions (PGDs) 87.1 and 90.1. Parents may prefer not to wait for the cream to work if waiting is going to distress the child/young person. Ethyl Chloride spray may be a suitable alternative or supplying the cream before the hospital visit with instructions for parents to apply before coming to hospital.

### 3.4.7. Accident and Emergency

Accident and Emergency can be overwhelming for a child/young person with ASC.

- The triage nurse should establish that the patient has ASC and discuss with carers the most appropriate area for the patient to be treated in
- Try to limit the number of staff caring for the patient- allocate a key person if possible.
- Dependent on departmental pressure the staff should try and minimise the length of time the patient will have to wait to be seen.

- Keep the family informed as to why they are waiting
- Allow the parent/carer to stay with the child/young person whilst treatment is being given whenever possible (if the parent is comfortable with this arrangement).
- If the child/young person requires admission to the ward ensure this happens promptly and that the flow through the department is constant.

### 3.4.8. Admission to hospital

Always consider the sensory environment when admitting Autistic children and young people. In some cases, it may be preferable to admit the child to a side room if available or clinically required. If unavailable look at admitting the child/young person to the quietest area of the ward e.g. away from crying babies, noisy machines, televisions etc.

If the admission is elective encourage the child/young person and family to attend the pre assessment process to familiarise the child/young person to new surroundings, look at specific requirements of the individual child/young person(with specific reference to the child's/young person's daily routine) and begin the preparation process for surgery.(play therapists will be a pivotal role in preparing the child/young person and family). *Some families may feel that attending the pre assessment clinic may be more stressful for the child/young person than not attending. A telephone conversation may be more appropriate in these circumstances particularly with regard to finding out the individual child's/young person's specific requirements*.

Encourage the family to bring in any communication tools they use at home (e.g. picture boards).

Encourage the parent or carer to stay in hospital with the child/young person if possible.

Plan in advance as best as possible to pre-empt any likely delays e.g. waiting for discharge medications.

Ensure all Multi-disciplinary Team members are aware of the admission of the child/young person so that the additional needs of children/young people with SCD can be considered and unnecessary delays avoided.

### 3.4.9. Clinical Audit Standards derived from guideline

To ensure that this policy is compliant with the above standards, the following monitoring processes will be undertaken:

- A retrospective review of complaints, PALS reports and incidents will be conducted and any issues addressed.

- A staff questionnaire will be undertaken to ascertain staff understanding of the guideline and to address any training issues that arise as a consequence.

The audit results will be sent to Senior Nurse, Paediatric Inpatients, and the Clinical Director for Paediatrics who will review the results and make recommendations for further action.

## 4. References

Autism Steering Committee, North Shore – Long Island Jewish Health System (2004)"Your next patient has Autism" Bethpage,NY:Fay J Linder Cebter for Autism

Maureen E Brown. (2006) "Communicating with the child who has autistic spectrum disorder: a practical solution" Paediatric Nursing. Volume 18 no 1.

Morton-Cooper A. (2004) "Health care and the autistic spectrum: a guide for health professionals', patients and carers. London: Jessica Kingsley. Available from NAS Publications Department.

NICE Guidance: Autism spectrum disorder in under 19s: support and management. Clinical guideline [CG170] Published date: August 2013. Reviewed 2016www.northshorelij.com/body.cfm?id=2851.

Screening electroencephalograms in spectrum disorders: evidence based guideline (2005) Kagan-Kushnir,T, Roberts S.W and Snead O.C 'Journal of Child Neurology' 2005 Vol 20(3) pp197-206.

The National Autistic Society
"Patients with autistic spectrum disorders - information for health professionals"
www.nas.org.uk

## 5. Audit of the process

Compliance with the process will be monitored through the following:

| Key elements | Process for Monitoring | By Whom (Individual / group /committee) | Responsible Governance Committee /dept | Frequency of monitoring |
|---|---|---|---|---|
| Reasonable adjustments will be made for autistic children and young people | Audit | CYP LD&A Specialist Nurse | Children's Board | Annual |
|  |  |  |  |  |

The audit results are to be discussed at relevant governance meetings (o review the results and recommendations for further action. Then sent to Mental Health and Complex Care Board who will ensure that the actions and recommendations are suitable and sufficient.

## 6. Equality Impact Assessment (EIA)

| | |
|---|---|
| **Type of function or policy** | Existing |

| | | | |
|---|---|---|---|
| **Division** | Corporate | **Department** | Complex Health Hub |
| **Name of person completing form** | Lydia Smith | **Date** | 28/02/2023 |

| **Equality Area** | **Potential Negative Impact** | **Impact Positive Impact** | **Which groups are affected** | **Full Impact Assessment Required YES/NO** |
|---|---|---|---|---|
| Race | No | No | | No |
| Pregnancy & Maternity | No | No | | No |
| Disability | No | Yes | | No |
| Religion and beliefs | No | No | | No |
| Sex | No | No | | No |
| Gender reassignment | No | No | | No |
| Sexual Orientation | No | No | | No |
| Age | No | No | | No |
| Marriage & Civil Partnership | No | No | | No |
| **EDS2 – How does this change impact the Equality and Diversity Strategic plan (contact HR or see EDS2 plan)?** | | | | |

- **A full assessment will only be required if: The impact is potentially discriminatory under the general equality duty**
- **Any groups of patients/staff/visitors or communities could be potentially disadvantaged by the policy or function/service**
- **The policy or function/service is assessed to be of high significance**

**IF IN DOUBT A FULL IMPACT ASSESSMENT FORM IS REQUIRED**

**The review of the existing policy re-affirms the rights of all groups and clarifies the individual, managerial and organisational responsibilities in line with statutory and best practice guidance.**