

Northumberland Children and Young People's Under 19 Years Autistic Spectrum Disorder (ASD) Pathway

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Read in conjunction with '*Northumberland Sources for Advice for ASD (Thrive Model)*'. This document outlines possible sources of support that are available before, during and after diagnostic assessment.

Young people age 19 and above will follow the 'Adult ASD Diagnostic Pathway'.

Appendix A provides guidance on the presentation of females on the Autistic Spectrum.

Context

The pathway below sets out the support that is available to assist children and young people (and their families) in Northumberland where unmet needs may be due to an underlying Autistic Spectrum Disorder (ASD). The pathway is based on the Thrive model which has been adopted across Northumberland to ensure an appropriate level of support for identified needs.

The goal of this pathway is to ensure that children and young people gain appropriate support, are assessed and referred appropriately as needed. It is aimed at parents and practitioners from a wide variety of agencies and other adults that have regular contact with children and young people.

- To improve the quality of support, advice and guidance offered to children, young people and their parents or carers when the difficulties being experienced may be related to an underlying ASD.
- Offer consistent and child focused support to children, young people and their families.
- To increase the knowledge, skills and competence of staff to recognise and respond appropriately when a young person is experiencing difficulties due possibly to an underlying ASD.

NB: Not all children and young people referred for an assessment will receive a diagnosis.

Identifying Possible ASD in children and Young People

The following is taken from 'NICE Pathways: "Identifying Possible Autism in Children and Young People' <https://pathways.nice.org.uk/pathways/autism-spectrum-disorder>.

Guidance Notes

- Use the lists below to help identify the signs and symptoms of possible autism in the age groups identified.
- Do not rule out autism if the exact features described below are not evident; they should be used for guidance, but do not include all possible manifestations of autism.
- The signs and symptoms are a combination of delay in expected features of development and the presence of unusual features, and are intended to alert professionals to the possibility of autism in a child or young person about whom concerns have been raised.
- They are not intended to be used alone, but to help professionals recognise a pattern of impairments in reciprocal social and communication skills, together with unusual restricted and repetitive behaviours.

Signs and symptoms of possible autism in children aged 0 - 4 years or equivalent developmental stage

Social Interaction and Reciprocal Communication Behaviours

Spoken language

- Language delay (in babble or words, for example less than ten words by the age of 2 years)
- Regression in or loss of use of speech.
- Spoken language (if present) may include unusual:
 - non-speech like vocalisations
 - odd or flat intonation
 - frequent repetition of set words and phrases initially spoken by others ('echolalia')
 - frequent repetition of own speech formations ("palalia")
 - reference to self by name or 'you' or 'she/he' beyond 3 years.
 - reduced and/or infrequent use of language for communication, for example use of single words although able to speak in sentences.

Responding to others

- Absent or delayed response to name being called, despite normal hearing.
- Reduced or absent responsive social smiling.
- Reduced or absent responsiveness to other people's facial expressions or feelings.
- Unusually negative response to the requests of others (demand avoidant behaviour).
- Rejection of cuddles initiated by parent or carer, although may initiate cuddles themselves.
- Inappropriate responses to the initiation of social contact such as ignoring questions or responding by changing the topic of conversation.

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space.
- Reduced or absent social interest in others, including children of his/her own age – may reject others; if interested in others, may approach others inappropriately, seeming to be aggressive or disruptive.
- Reduced or absent imitation of others' actions.
- Reduced or absent initiation of social play with others, plays alone.
- Reduced or absent enjoyment of situations that most children like, for example, birthday parties.
- Reduced or absent sharing of enjoyment.
- May have difficulties maintaining conversation, may use frequent statements of fact as a means to engage.

Eye contact, pointing and other gestures

- Reduced or absent use of gestures and facial expressions to communicate (although may place adult's hand on objects).
- Reduced and poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people's eyes when speaking) and speech used in social communication.
- Reduced or absent social use of eye contact, assuming adequate vision.
- Reduced or absent joint attention shown by lack of:
 - gaze switching
 - following a point (looking where the other person points to – may look at hand)
 - using pointing at or showing objects to share interest.

Ideas and imagination

- Reduced or absent imagination and variety of pretend play. Imaginary play may be “scripted” or copied.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking.
- Repetitive or stereotyped play, such as playing in the same manner over and over.
- Repetitive behaviours which do not appear play related such as opening and closing doors, tearing paper.
- Restricted and Over-focused to the exclusion of other age appropriate interests or unusual interests.
- Excessive insistence on following own agenda.
- Extremes of emotional reactivity to change or new situations, insistence on things being 'the same'.
- Over or under reaction to sensory stimuli, for example textures, sounds, smells.
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads.

Signs and symptoms of possible autism in children aged 5 to 11 or equivalent developmental stage

Social interaction and reciprocal communication behaviours

Spoken language

- Spoken language may be unusual in several ways:
 - very limited use monotonous tone repetitive speech,
 - may use a variety of accents not in keeping with upbringing or locality
 - speech may be usual in terms of volume and/or rate
 - frequent use of stereotyped (learnt) phrases
 - content dominated by excessive information on topics of own interest
 - talking 'at' others rather than sharing a two-way conversation
 - responses to others can seem rude or inappropriate.
 - may use made up words or language

Responding to others

- Reduced or absent response to other people's facial expression or feelings.
- Reduced or delayed response to name being called, despite normal hearing.
- Subtle difficulties in understanding others intentions; may take things literally and misunderstand sarcasm or metaphor.
- Unusually negative response to the requests of others (demand avoidant behaviour).
- Inappropriate responses to the initiation of social contact such as ignoring questions or responding by changing the topic of conversation. May respond by answering questions with an unrelated topic.

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space.
- Reduced or absent social interest in people, including children of his/her own age – may reject others; if interested in others, may approach others inappropriately, seeming to be aggressive or disruptive.

- Reduced or absent greeting and farewell behaviours.
- Reduced or absent awareness of socially expected behaviour.
- Reduced or absent ability to share in the social play or ideas of others, plays alone.
- Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar.
- Reduced or absent enjoyment of situations that most children like.

Eye contact, pointing and other gestures

- Reduced and poorly integrated gestures, facial expressions and body orientation, eye contact (looking at people's eyes when speaking) and speech used in social communication.
- Reduced or absent social use of eye contact, assuming adequate vision.
- Reduced or absent joint attention shown by lack of:
 - gaze switching
 - following a point (looking where the other person points to may look at hand)
 - using pointing at or showing objects to share interest.
 - over exaggerated use of gesture and facial expression.

Ideas and imagination

- Reduced or absent flexible imaginative play or creativity, although scenes seen on visual media (for example, television) may be re-enacted.
- Makes comments without awareness of social niceties or hierarchies.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking.
- Play repetitive and oriented towards objects rather than people.
- Over-focused or unusual interests.
- Rigid expectation that other children should adhere to rules of play.
- Excessive insistence on following own agenda.
- Extremes of emotional reactivity that are excessive for the circumstances.
- Strong preferences for familiar routines and things being 'just right'.
- Dislike of change, which often leads to anxiety or other forms of distress (including aggression).
- Over or under reaction to sensory stimuli, for example textures, sounds, smells.
- Excessive reaction to taste, smell, texture or appearance of food or extreme food fads.

Other factors that may support a concern about autism

- Unusual profile of skills or deficits (for example, social or motor coordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age).
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers.

Signs and symptoms of possible autism in young people aged 12 to 18 or equivalent developmental stage

Social interaction and reciprocal communication behaviours

Spoken language

- Spoken language may be unusual in several ways:
 - very limited
 - use monotonous tone
 - repetitive speech, frequent use of stereotyped (learnt) phrases, content dominated by excessive information on topics of own interest
 - talking 'at' others rather than sharing a two-way conversation
 - responses to others can seem rude or inappropriate.

Interacting with others

- Reduced or absent awareness of personal space, or unusually intolerant of people entering their personal space.
- Long-standing difficulties in reciprocal social communication and interaction: few close friends or reciprocal relationships.
- Reduced or absent understanding of friendship; often an unsuccessful desire to have friends (although may find it easier with adults or younger children).
- Social isolation and apparent preference for aloneness.
- Reduced or absent greeting and farewell behaviours.
- Lack of awareness and understanding of socially expected behaviour.
- Problems losing at games, turn-taking and understanding 'changing the rules'.
- May appear unaware or uninterested in what other young people his or her age are interested in.
- Unable to adapt style of communication to social situations, for example may be overly formal or inappropriately familiar.
- Subtle difficulties understanding others' intentions; may take things literally and misunderstand sarcasm or metaphor.
- Makes comments without awareness of social niceties or hierarchies.
- Unusually negative response to the requests of others (demand avoidant behaviour).

Eye contact, pointing and other gestures

- Poorly integrated gestures, facial expressions, body orientation, eye contact (looking at people's eyes when speaking) assuming adequate vision, and spoken language used in social communication.

Ideas and imagination

- History of a lack of flexible social imaginative play and creativity, although scenes seen on visual media (for example, television) may be re-enacted.

Unusual or restricted interests and/or rigid and repetitive behaviours

- Repetitive 'stereotypical' movements such as hand flapping, body rocking while standing, spinning, finger flicking.
- Preference for highly specific interests or hobbies.
- A strong adherence to rules or fairness that leads to argument.
- Highly repetitive behaviours or rituals that negatively affect the young person's daily activities.
- Excessive emotional distress at what seems trivial to others, for example change in routine.
- Dislike of change, which often leads to anxiety or other forms of distress including aggression.
- Over or under reaction to sensory stimuli, for example textures, sounds, smells.
- Excessive reaction to taste, smell, texture or appearance of food and/or extreme food fads.

Other factors that may support a concern about autism

- Unusual profile of skills and deficits (for example, social or motor coordination skills poorly developed, while particular areas of knowledge, reading or vocabulary skills are advanced for chronological or mental age).
- Social and emotional development more immature than other areas of development, excessive trusting (naivety), lack of common sense, less independent than peers.

When to refer a child or Young Person for a Diagnostic Assessment

The following is taken from 'NICE Pathways: "Referral of under 19s with possible autism spectrum disorder". <https://pathways.nice.org.uk/pathways/autism-spectrum-disorder>

If the child or young person is not currently under a Speech and Language Therapist a referral to a Northumbria Speech and Language Team should be considered.

Child Displaying Signs of Regression

- Refer children younger than 3 years to a community paediatrician if there is regression in language or social skills.
- Refer to a Paediatrician or Paediatric Neurologist (who can refer on to the Northumbria Preschool ASD pathway, or CYPS if necessary) a child or young person:
 - older than 3 years with regression in language
 - of any age with regression in motor skills.

Concern about signs or symptoms but no regression

Consider referring children and young people to a community paediatrician (for children under 4 years and 10 months) or CYPS if you are concerned about possible autism on the basis of reported or observed signs and/or symptoms listed above.

Take account of:

- the severity and duration of the signs and/or symptoms
- the extent to which the signs and/or symptoms are present across different settings (for example, home and school)
- the impact of the signs and/or symptoms on the child or young person and their family
- the level of parental or carer concern and, if appropriate, the concerns of the child or young person
- the likelihood of an alternative diagnosis
- factors associated with an increased prevalence of autism

Factors associated with an increased prevalence of autism

- A sibling with autism.
- Birth defects associated with central nervous system malformation and/or dysfunction, including cerebral palsy.
- Gestational age less than 35 weeks.
- Parental schizophrenia-like psychosis or affective disorder.
- Maternal use of sodium valproate in pregnancy.
- A learning (intellectual) disability.
- ADHD.
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms.
- Chromosomal disorders such as Down's syndrome.
- Genetic disorders such as fragile X.
- Muscular dystrophy.
- Neurofibromatosis.
- Tuberous sclerosis.

If you have concerns about development or behaviour but are not sure whether the signs and/or symptoms suggest autism, consider: consulting a member of the SEND Autism Support Service or Health Professionals who can provide advice to help you decide if a referral to the autism team is necessary or referring to another service. That service can then refer to the autism team if necessary

Insufficient concern to refer immediately for a diagnostic assessment, referral declined by parents/carers/young person or lack of signs and symptoms

- If you do not think concerns are sufficient to prompt a referral, consider a period of watchful waiting and if required seek support from alternative health or education services. If concerns persist reconsider your referral decision.
- If the parents or carers (or when relevant the child or young person) prefer not to be referred for an assessment, consider a period of watchful waiting and if required seek support from alternative health or education support services. If concerns persist ask the parent/young person if they would like to reconsider their referral decision.
- If a concern about possible autism has been raised but there are no signs, symptoms or other reasons to suspect autism, use professional judgment to decide what to do next.

Referral to the relevant service to undertake further assessment of a child or young person's needs:

In Northumberland the usual route of an ASD referral for children 4 years 10 months and below would be via a Health Visitor, GP, School Health Nurse or Speech and Language Therapist to a Community Paediatrician.

<https://www.northumbria.nhs.uk/our-services/childrens-services/>

For Children and young people of school age (over the age of 4 years 10 months) the usual route for referral would be via school staff, health professionals or SEND support services to the Children and Young People's Service (CYPS).

Northumberland CYPS
Craster
St Georges Park
Morpeth
Northumberland
NE61 2NU

Ntawnt.notcyps@nhs.net

A referral made via either of the routes identified above will result in an initial general assessment being carried out followed by additional targeted assessments tailored to specific need.

When referring children and young people to the appropriate Autism Team, include in the referral the following information:

- reported information from parents, carers and professionals about the signs and/or symptoms of concern
- observations of the signs and/or symptoms present in specific settings/environments
- family circumstances that may be relevant to the child's development.
- the views of all adults with parental responsibility for the child or young person
- that parents have consented to the information contained within the referral being shared.

In addition, include the following information, if available:

- antenatal and perinatal history

- developmental milestones
- factors associated with an increased prevalence of autism [see information included above] relevant medical history and investigations
- information from previous assessments.

NB: In some circumstances further information may need to be collected prior to an assessment being undertaken.

This pathway has been designed by the following organisations:	Northumberland CCG Northumberland Public Health Northumberland Local Authority Northumbria Healthcare Northumberland, Tyne and Wear NHS Foundation Trust
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Appendix A

Females on the Autistic Spectrum - Additional Information

How do women and girls experience autism?

<https://www.autism.org.uk/about/what-is/gender/stories.aspx>

Extract taken from 'Girls and Autism: Flying Under the Radar' NASEN (2016)

<https://nasen.org.uk/uploads/assets/c6c70871-4de8-410f-a444ef1efa0261a6/flying-under-the-radar.pdf>

Learning Characteristics

Possible characteristics of girls with ASD

- Difficulties with abstract concepts and auditory processing
- Likes routine, dislikes change
- Quiet, shy, awkward, compliant, passive
- Not asking for help, or being avoidant, to mask difficulty
- Explosive outbursts or meltdowns
- Perfectionist
- Very determined and likes to be in control
- Fine motor or sensory difficulties

Social Characteristics

Girls with ASD may:

- Mirror behaviour
- Affect different personalities and may not have a strong sense of identity
- Be socially immature and vulnerable
- Try to impose scripted, controlling play on peers

Emotional Characteristics

Girls with ASD may:

- Need to feel that someone 'gets' them
- Camouflage emotions or mask symptoms at school
- Be exhausted from the pressure of constant social imitation/mirroring
- Experience anxiety more intensely than others
- Shut down or cry over small things due to being overwhelmed
- Experience sensory/emotional overload
- Hate injustice

Females on the Autism Spectrum (Posters) - The Little Black Duck

<https://www.thelittleblackduck.com.au/product/females-on-the-autism-spectrum-new/>

This organisation has created a poster that outlines key characteristics that may be observed in females on the autistic spectrum. The poster is divided into 3 sections key sections: Behaviour, Communication and Social Characteristics. The full list of characteristics are outlined in the resource description.