

Autism Spectrum Disorder Pathway

<u>Logo</u>	<u>Organisation</u>	<u>CEO</u>	<u>Signature</u>	<u>Date</u>
	Child & Adolescent Mental Health Service	Antony Sheehan		Dec'08
	Children's Community Health Service	Paul Miller		Sep '08
	Leicester City NHS Primary Care Trust	Tim Rideout		Sep 08
	Leicestershire County and Rutland NHS Primary Care Trust	Catherine Griffiths		Nov '08
	Leicester City Children and Young People's services	Andrew Bunyan		Aug '08
	Leicestershire Children and Young People's services	Gareth Williams		Oct '08
	Rutland Children and Young People's Services	Carol Chambers		Dec '08

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Autism Spectrum Disorder Pathway

Introduction

The purpose of this guidance is to describe expected practice in relation to children whose needs may fall on the autism spectrum (see Appendices 1 and 2). It focuses particularly on the importance of joint working among professionals when an autism spectrum disorder is suspected. All relevant agencies in Leicestershire, Leicester and Rutland, which employ professionals involved in making a diagnosis of autism have agreed that this protocol will be followed.¹

Why is the Integrated Care Pathway being developed now?

For a number of years this has been an area of ongoing work involving local professionals working together to develop local guidance. The following drivers have ensured that this work is embedded in local practice.

The **National Service Framework for Children, Young People's and Maternity Services (Department of Health, 2004)** articulated the need for specialist services for children with Autism Spectrum Disorders to be provided in a seamless fashion as close to the child's locality as possible (Standard 9). It stressed the importance of multidisciplinary and inter-agency working in order to meet the child's needs effectively and without undue delay, and emphasised that universal services have a clear role to play in child mental health, though some children and young people also need ready access to appropriately skilled specialist mental health professionals.

The **SEN Code of Practice (DfES, 2001)** also stresses the importance of *early identification, use of best practice in meeting needs, partnership working between parents and professionals, multidisciplinary approaches to service provision and timely intervention*. Although these principles apply specifically to educational needs, the overarching themes are replicated in the broader '**Every Child Matters**' agenda. 'Every Child Matters' recognises the need to bring services together, work in a multidisciplinary 'team around the child' and to focus on the needs of the child in the home, community and education settings.

The **National Autism Plan for Children (NIASA, 2003)** sets out the need for a co-ordinated approach for the identification, assessment and diagnosis of children with Autism Spectrum Disorders. Current practice varies considerably across the country and the National Autism Plan for Children sets out best practice in diagnostic assessment, making it clear that this should be multi-agency, and include observations of the child across different settings in addition to taking the early developmental history from parents/carers.

¹ Please note that the terms "identification" and "diagnosis" are used interchangeably in this document.

What is the Purpose of the Pathway?

It is recognised that early identification is important for the future of children with Autism Spectrum Disorders. Hence, the purpose of this pathway is to describe expected practice in relation to supporting children whose needs may fall on the Autism Spectrum. It focuses particularly on the importance of joint working among professionals when an Autism Spectrum Disorder is suspected or where there are differences of opinion between professionals.

A large number of professionals in different agencies work with children who have been identified with an Autism Spectrum Disorder, which may involve specialist intervention. The Autism Spectrum Disorder pathway is designed to help professionals know where to go for additional help for the child. Also to make the process as clear and timely as possible, ensuring that the child and family receive the appropriate input at the right time. Most importantly, the Pathway should allow children, young people and their parents to understand how the various services will work together, with the aim of obtaining the best outcome as soon as possible.

Assessment

The Autism Spectrum Disorder Pathway will involve new ways of working with creative and positive thinking and practice. It should limit repetition, potential confusion and the hurdles families often face and offer the opportunity for early support (even in the absence of confirmed identification of the problem, such as an Autism Spectrum Disorder). A guiding principle of this work is that whenever possible, a child's presenting needs should be met from within universal services (such as Education), since in reality, this is where they will spend much of their time. However, in some cases a child and family may require an additional, more specialist level of intervention (such as from Child and Adolescent Mental Health Services or Children's Community Health Service) to *inform* or *enhance* how the child will continue to be managed in the universal setting. This involves a graduated approach in which more specialist services may be incrementally *added* to the universal services on the basis of individual need, but without in any way replacing them.

When concerns arise from a professional about a child's development, it is expected that people in contact with the child and family should get in touch with support services for advice, as per local referral guidelines

Wherever concerns originate, or are first expressed by a parent/carer, it is expected that the practitioner involved will ensure further investigation and observations are undertaken. For all children with additional needs, it is expected that a holistic view of the child will be undertaken, which may include using the Common Assessment Framework (CAF), as described within the Every Child Matters document. This should be discussed with the parent(s)/carer(s).

The Role of Parents/Carers

Parents/carers are essential partners in the assessment process as they are an invaluable source of information. While we recognise that practitioners may have a range of hypotheses, especially in the early stages of investigation, it is considered good practice that parents be included in and aware of these hypotheses. It is important that such information is co-ordinated amongst the professionals involved with the family to avoid mixed, or confusing, messages. Precisely how this information should be shared with parents is a matter for professional judgement.

Working towards a diagnosis of Autism Spectrum Disorder

This section should be read in conjunction with the Flowchart on page 8.

Stage 1: Initial concerns re. communication /social interaction & gathering information

- Health Practitioners should consider either a Single Point of Access (SPA) referral to Children's Community Health Service (CCHS) or a SPA referral to Child and Adolescent Mental Health Services (CAMHS) (see flow chart and information below), unless the child is already known to them. This is to explore other possible explanations for the child's presentation.
- Education Practitioners should consult with appropriate supporting professionals in line with the SEN Code of Practice to seek to meet the child's needs. If an Autism Spectrum Disorder is suspected then a referral should be made to CCHS or CAMHS (see Stage 2 below).
- A professional who will be the lead for the child's assessment should be identified out of all the professionals involved with the family and child (this may be done as part of the CAF). This lead person should be someone who is working closely with the family and can be self appointed (with the family's consent). Once the lead person is identified then the other professionals and parents should be informed (preferably in writing).

Stage 2: Referral for Health Assessment

- Children with these difficulties should be seen by either CCHS or CAMHS to consider and exclude any additional health needs or other diagnosis. Indicators for which service to refer are outlined below.
 - a. Referrals to CCHS should be considered if
 - i. The child is under 7 years old AND/OR
 - ii. There are any concerns about a child's development AND/OR
 - iii. There are concurrent medical issues such as possible seizures or regression

- b. Referrals to CAMHS should be considered if
 - i. There are suspected associated mental health problems (such as Obsessive Compulsive Disorder, Tourette's, mood disorders, severe anxiety or possible psychosis) AND/OR
 - ii. The child is 13 years old or older AND/OR
 - iii. The child is 'post adoption' or currently being 'Looked After' (as attachment difficulties can present in a similar way)
- c. Children who are over 7 years old but under 13 years old and have no other needs, as outlined above in parts a and b, may be referred to either service.
- d. When a referral is received by a service (for example received by CAMHS) is felt to be inappropriate for that service, then the following options are available
 - i. If the letter clearly indicates (as per the criteria in part a and b above) that the referral should have gone to the other service, then the referral letter should be faxed across to the other service with a standard note sent to the referrer to let them know.
 - ii. If after assessment by one service it is felt that there is a clear indication for handover to the other service (as per the criteria in part a and b above), then a referral letter should be sent to the SPA for the other service. Please see * below
 - iii. If after assessment by one service, a second opinion is sought from the other service, then a request for a second opinion should be sent to the SPA for the other service. Please see * below
 - iv. If after assessment it is felt that a joint assessment is indicated with the other service, then a request for a joint opinion should be sent to the SPA of the other service. Please see * below

* Any referrals from one service to another (for a referral, second opinion or joint assessment) should include all relevant assessments (including the child's educational attainment and/or developmental level).

- Referral to Speech and language therapy to be considered (if SLT not involved)

Stage 3: Comprehensive Assessment

- The lead person should consult all other agencies involved with the child, with parental permission, as part of the assessment process.
- Professionals have a duty to respond to requests for such consultations.
- The information gathered should include observations in, and/or information from, different settings and an early developmental history. It should also include information on the child's strengths and interests.
- A multiagency meeting (including parents where appropriate) should be held wherever possible to share information, reach a conclusion and to identify roles and actions to be taken. If a multiagency meeting is held it should be arranged by the

lead professional for the child and should include as a minimum the lead professional and one other professional. At least 2 agencies should be represented at the meeting. A minimum of 2 professionals who are able to make a diagnosis (clinical psychologist, educational psychologist or doctor) need to be involved in the identification. The lead person should also seek information from all the professionals involved who are unable to attend the meeting.

- In the event that a multidisciplinary meeting cannot be held within a reasonable time frame, then the lead professional should gather information from all the different agencies involved (via reports or telephone). When professionals supply information in this way (rather than via a meeting), the professionals need to ensure that their view of whether there are any difficulties (or not) with the child's social and communication skills, is clearly indicated. The lead professional should inform the other professionals involved if there is any difference of opinion when they collate the information.

Stage 4: Outcome of Assessment

- Once the professionals involved in the assessment are satisfied that uncertainties have been resolved, and that Autism Spectrum Disorder is identified, this should be confirmed in a face to face meeting with the parents/carers (if this has not already taken place at Stage 3). Information about available support and agencies (such as that in the ASD information pack) should be given to the parents at this meeting. The identification of an ASD should then be confirmed in writing to the parents/carers.
- There should be a discussion with the family about how and when to share the outcomes of the process with the child/young person, taking into account their age, developmental level and parental wishes.
- If the lead professional should need to change at this point, parents must be informed.
- All children should have a care plan.
- Where more time is required for assessment (for a child to develop, or for interventions to be evaluated), parents should be informed verbally and in writing what the next steps are and when the circumstances will be reviewed.
- Where there is disagreement within the group of professionals involved with the child as to the outcome, the practitioners should seek a joint assessment with CAMHS/CCHS. Then if a disagreement still exists, the practitioners should request a review of all of the evidence by the Autism Reference Group.
- Where parents disagree with the outcome, it is important to try to resolve the disagreement amicably. This may involve identifying and clarifying the nature of the disagreement, consulting with colleagues and advising parents of the possible next steps, including consideration by the Autism Reference Group.

Stage 5: Transition(NSF Standard 4 Growing up into Adulthood)

- Multiagency working with the team around the child continues for as long as necessary. Transition arrangements for young people above 13 years old will be supported by a Transitions Personal Advisor (PA) and in some cases a specialist PA, from the Connexions Service and referrals are made through the school SENCo or by approaching the Connexions bases within the child's local community.
- Protocols have yet to be negotiated to inform the progression to adult services for Autism Spectrum Disorders.

Role of the Autism Reference Group

The Autism Reference Group is made up of professionals from all of the agencies involved in the diagnosis and support of children with Autism Spectrum Disorders, and at least one parent.

When approached for guidance, the Group expects that all parties involved will share their evidence with the Group. The Group will aim to:

- Clarify sources of the discrepancy in opinions
- Identify the means to resolve these.

Parental consent must be obtained before the Autism Reference group is approached.

The Autism Reference Group can be contacted via the current chair of the Autism Reference Group who can be contacted via either

- Jenny Cornwell (parent representative and member of Leicester National Autistic Society) on 07775 777524
- or the secretary to Dr Shawcross on 0116 225 6745.

Appendices

Appendix 1 – What is an Autism Spectrum Disorder?

The term “Autism Spectrum Disorder” is used to describe a range of conditions, which share certain core features. However, the picture is unique to each individual, depending on factors such as gender, age, ability and personality style and may vary in degree and expression.

All children with an Autism Spectrum Disorder have difficulties in the following three areas, known as the “Triad of Impairments.”

- a. Difficulty with social understanding and relationships with adults and children
- b. Difficulty with social communication and language
- c. Difficulty with social imagination (i.e. difficulties with flexibility of thought and behaviour)

In addition, their sensory perception and processing is often different from other children (Bogdashina, 2003). They can be hypo or hyper sensitive and can have difficulty selecting out what is relevant, thus being overwhelmed or confused by sensory information.

(For more details on the Triad of Impairments, please see Appendix 2)

Difficulties in these areas must be present before the age of 36 months for a diagnosis to be made (ICD-10, WHO, 1992), although such difficulties can be missed in the early years so that the diagnosis often occurs at a much later age, particularly in the more able group. While all children may show some or all of these difficulties at some time or another, where they are **continuing, occur in more than one setting** and/or are at a level **unusual for the child’s age**, the matter should be investigated.

How many people have an Autism Spectrum Disorder?

Diagnosis is based on observation and history taking and there is no definitive test for ASD. A Medical Research Council review on Autism states that there is likely to be about 60 per 10,000 children with an ASD under the age of 8 years. This rate is likely to increase with age, as more children are identified. More boys are diagnosed as having an ASD (overall ratio 4:1) than girls, particularly in the more able group.

What causes an Autism Spectrum Disorder?

There is evidence from twin studies and studies of family members that genetic factors are involved in ASD, probably with the involvement of several genes. Several environmental factors and possible triggers are also being researched.

Are children with Autism Spectrum Disorders more likely to have other problems?

As traditional methods of learning require good communication skills, then all children with an ASD will need staff to be aware of learning styles for children with ASD. About 70% of children with autism also have additional learning difficulties and will be delayed in their development. About 30% of children with autism and all of those with Asperger Syndrome will be of average or above average intellectual ability and can do very well academically. However, their good academic skills may mask their difficulties in social and emotional understanding, problem-solving and independent living skills. Children with ASD are more likely to have epilepsy, hearing difficulties, visual problems, sensory problems, motor problems, difficulties sleeping and dietary problems.

Some medical conditions are also commonly associated with Autism Spectrum Disorders. These include conditions such as Fragile X syndrome, Rett Syndrome, Down Syndrome and Tuberous Sclerosis.

Can children with Autism Spectrum Disorder be helped?

It is generally accepted that ASD is a lifelong condition and that education is the most effective intervention (NIASA, 2003). With appropriate support and interventions, children can develop strategies to help address the difficulties they have in social understanding, interaction and communication, so that with time, their ASD might be less apparent and disabling.

References

Medical Research Council (2001) *Review of autism research: epidemiology and causes*, London: Medical Research Council

National Initiative for Autism: Screening and Assessment (2003) *National Autism Plan for Children*, London: National Autistic Society

Appendix 2 – The Triad of Impairments

As noted in Appendix 1, all children with Autism Spectrum Disorders have the following characteristics, described as the “Triad of Impairments.” These are:

- a. Difficulty with social understanding and relationships with adults and children
- b. Difficulty with social communication and language
- c. Difficulty with social imagination (i.e. difficulties with flexibility of thought and behaviour)

In addition, their sensory perception and processing is often different from other children (Bogdashina, 2003). They can be hypo or hyper sensitive and can have difficulty selecting out what is relevant, thus being overwhelmed or confused by sensory information.

The following notes elaborate on these three areas. Children with an ASD can be very different from one another so not all the features described will be seen in all children or to the same degree (both within and between genders).

a) Difficulty with social understanding and relationships with children and adults

Four different social subgroups have been identified in the autism spectrum (Wing, 1996). Children can change over time in terms of which group best describes them.

i) The aloof group

Children in this group are not people focused. They may behave as if other people do not exist. They may avoid physical contact from others (including hugs), unless this is initiated by them. They may walk past others without acknowledging their presence. They may use another’s hand to carry out tasks (e.g. open a fridge door), without looking at the person. This group is often described as being “in a world of their own.” Claire Sainsbury (2003), a very able woman with ASD says, “We are in your world, but we are just attending to different parts of it.”

If children take part in rough and tumble play, social contact may appear “typical” and appropriate, but the child will often return immediately to his or her “own world” once the game is over.

ii) The passive group

This group will accept social approaches from others but may not initiate social contact with children or their parents. Like the aloof group, they may avoid people and make very few demands on their parents/carers. They are often termed prematurely independent or as babies may be described as ‘too good’.

iii) The ‘active but odd’ group

Children in this group often make social approaches to others, most often with adults, but this often feels one-sided. The manner in which they make contact can be unusual and inappropriate (eg touching others; hitting others; interrupting loudly with a question about their special interest). Physical contact can be over-enthusiastic and they may cause pain

to others but not realise this – as they may have difficulties in interpreting and /or expressing pain. They may therefore be termed rude, selfish and aggressive, when this is not their intention at all. They fail to understand and appreciate others' needs and emotional feelings.

This group may be misdiagnosed as their active social approaches can mask their lack of understanding of how and why to interact socially.

iv) The over-formal, stilted group

This may be seen in those who are most able and who have a good level of spoken language. They may be excessively polite and formal in their behaviour and try hard to stick rigidly to the rules of social interaction. They have difficulty understanding these rules and have difficulty in understanding that these rules change with the social context.

b) Difficulty with verbal and non-verbal communication and language

All children and adults with Autism Spectrum Disorders have difficulties in understanding the purpose of communication and in how to communicate effectively. They often only communicate with others for a very limited range of functions (usually requests for objects or activities) and do not communicate for the simple pleasure of sharing ideas and observations with others. They may have problems in processing the spoken language of others and take language literally and so be confused with phrases such as 'Paint the child next to you' or with metaphor and jokes. Apart from children with Asperger Syndrome, all other children on the autism spectrum are delayed in developing spoken language by the age of 3 years and some of those children will need alternative forms of communication to speech. Children with good spoken language can have problems with holding conversations with difficulties with social timing, intonation, body language and in changing the focus from their interest to that of the listener.

c) Difficulties in flexibility of thought and behaviour

Children without ASD are usually able to adapt if situations change and can predict what they might do instead – often recalling similar, past experiences. This enables them to problem solve, to make choices and to engage with different social partners. In ASD, children find it very hard to work out what to do when their usual routine or activity is interrupted or can not be followed and this can cause great distress. It is very helpful if they are given visual reminders or suggestions of what they might do. They may not appreciate that toys represent the real object nor that they can pretend to be someone else in a game – and so find other ways to explore a toy car or train (eg spinning the wheels). Their play therefore often looks unconventional and they may need support in broadening out the range of play activities.

Once they have developed a particular routine (eg route to school) or way of doing an activity (drinking from a bottle), some children with ASD prefer to stick to this routine – as they know it works and they can succeed. Suggesting an alternative can be very anxiety-provoking as they can not then predict what might happen instead. Change therefore has to be gradually introduced and planned to reduce anxiety and panic.

Strengths and special interests

Not all children with ASD will have an area of exceptional talent or skill. However, it is very important for ALL children that their strengths, special interests and skills are assessed, recorded and made a part of their programme of support. Children with ASD are not as motivated by the usual social rewards, and so their special interests can act as incentives for working on less desirable activities or difficult areas.

It is worth noting that some able adults with ASD are keen to see ASD as Autism Spectrum Difference and not Autism Spectrum Disorder, as they maintain their way of being is a valid and successful way of being – and that they are only disabled when they are misunderstood and upset by others who do not know them and do not understand ASD.

Wing, L (1996)

The autistic spectrum: a guide for parents and professionals London: Constable

Appendix 3: Information for parents/carers on the diagnostic criteria that may be used during an assessment for a possible Autism Spectrum Disorder.

The two lists of diagnostic criteria below are from the DSM IV (The 4th Diagnostic and Statistical Manual of Mental Disorders) and ICD10 (The 10th International Classification of Diseases, WHO, 1992).

1. Diagnostic criteria for “Autistic Disorder” (DSM-IV, 1994):

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

- a) marked impairment in the use of multiple nonverbal behaviours, such as eye-to- eye gaze, facial expression, body postures, and gestures to regulate social interaction
- b) failure to develop peer relationships appropriate to developmental level
- c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- d) lack of social or emotional reciprocity

(2) qualitative impairments in communication, as manifested by at least one of the following:

- a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- c) stereotyped and repetitive use of language or idiosyncratic language
- d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities as manifested by at least one of the following:

- a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- b) apparently inflexible adherence to specific, non functional routines or rituals
- c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting or complex whole-body movements)
- d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

2. Diagnostic criteria for “Autism Disorder” (ICD-10; WHO 1992)

At least 8 of the 16 specified items must be fulfilled:

a) Qualitative impairments in reciprocal social interaction, as manifested by at least three of the following five:

- 1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction
- 2) failure to develop peer relationships
- 3) rarely seeking and using other people for comfort and affection at times of stress or distress and/or offering comfort and affection to others when they are showing distress or unhappiness
- 4) lack of shared enjoyment in terms of vicarious pleasure in other peoples' happiness and/or spontaneous seeking to share their own enjoyment through joint involvement with others
- 5) lack of socio-emotional reciprocity.

b) Qualitative impairments in communication:

- 1) lack of social usage of whatever language skills are present
- 2) impairment in make-believe and social imitative play
- 3) poor synchrony and lack of reciprocity in conversational interchange
- 4) poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes
- 5) lack of emotional response to other peoples' verbal and non-verbal overtures
- 6) impaired use of variations in cadence or emphasis to reflect communicative modulation
- 7) lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

c) Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following six:

- 1) encompassing preoccupation with stereotyped and restricted patterns of interest
- 2) specific attachments to unusual objects
- 3) apparently compulsive adherence to specific, non-functional routines or rituals
- 4) stereotyped and repetitive motor mannerisms
- 5) preoccupations with part-objects or non-functional elements of play material
- 6) distress over changes in small, non-functional details of the environment.

d) Developmental abnormalities must have been present in the first three years for the diagnosis to be made.

Appendix 4 – Glossary

ASD	Autism Spectrum Disorder
CAF	Common Assessment Framework
CAMHS	Child and Adolescent Mental Health Services
EP	Educational Psychologist
GP	General Practitioner
HV	Health Visitor
CCHS	Children's Community Health Service
SEN	Special Educational Needs
SENCo	Special Educational Needs Coordinator
SLT	Speech and Language Therapist
SPA	Single Point of Access (N.B. there are 2 separate SPA processes for CAMHS and CCHS)
SW	Social Worker

Appendix 5 – List of Parents and Professionals involved in Working Group for ASD Document

Dr K Bretherton	Consultant in Learning Disability (CAMHS)
Ms V Brown/Mrs R Leavesley	Speech and Language Therapists (CCHS)
Ms M Campbell	Early Years SEN Co-ordinator Leicester City Council
Ms J Gamble	Speech and Language Therapist (CCHS)
Ms M Gornall	Senior Educational Psychologist Leicester City Council
Mrs L Hardcastle	Parent Representative and member of Leicester branch of National Autistic Society (LNAS)
Dr M Hodgkinson	Consultant Child & Adolescent Psychologist (CAMHS)
Mr C Huddleston	Parent Representative and member of CLASP the Carers Centre & LNAS
Mr B James	Principal Educational Psychologist Rutland County Council
Dr K Karim	Consultant Child & Adolescent Psychiatrist (CAMHS)
Ms A Lewis	Parent Representative and member of Red Cross
Mr J Moran	Health Visitor
Dr A Shawcross	Consultant Community Paediatrician (CCHS)
Mr G. Thomas	Teacher (Autism Outreach Team County)
Mr R Westerman	Joint Principal Educational Psychologist Leicestershire County Council