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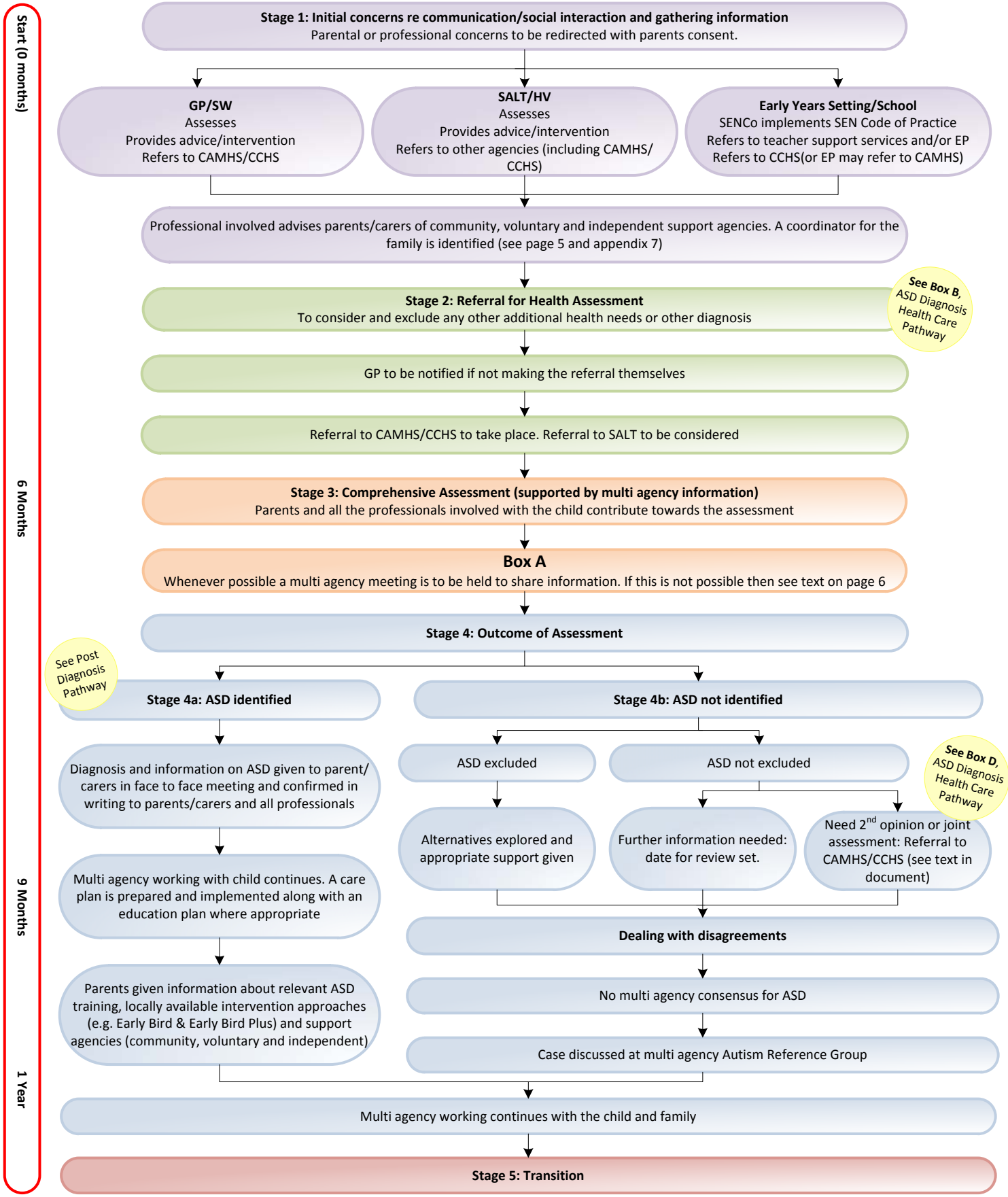
# Guidance for Multi Agency Professionals
# Integrated Care Pathway for Autism Spectrum Disorders
# Leicester, Leicestershire and Rutland

The following should be read in conjunction with the multiagency Autism Spectrum Disorder Pathway document and Appendix 4



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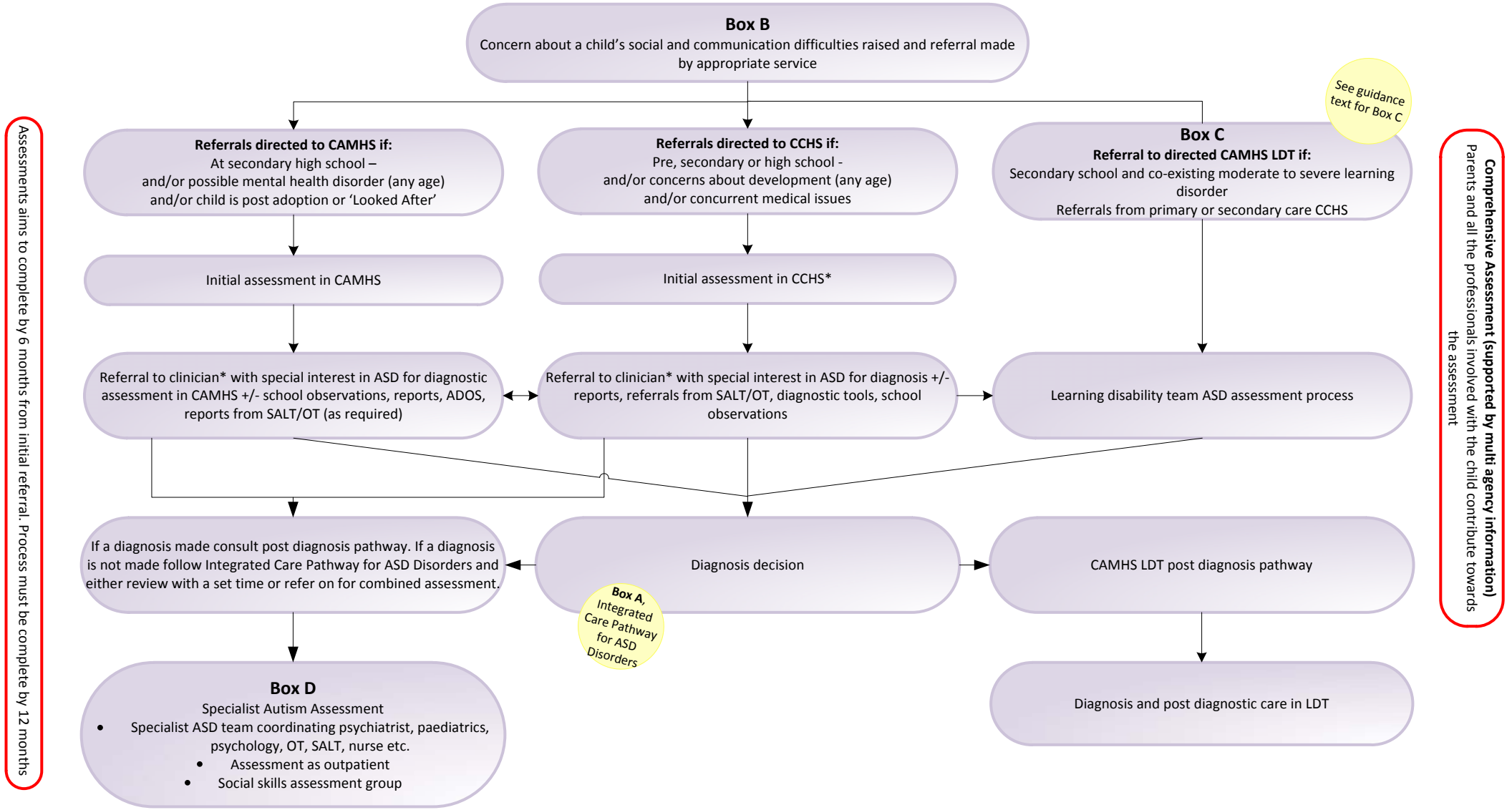
# Draft ASD Diagnosis Health Care Pathway




* May be the same clinician

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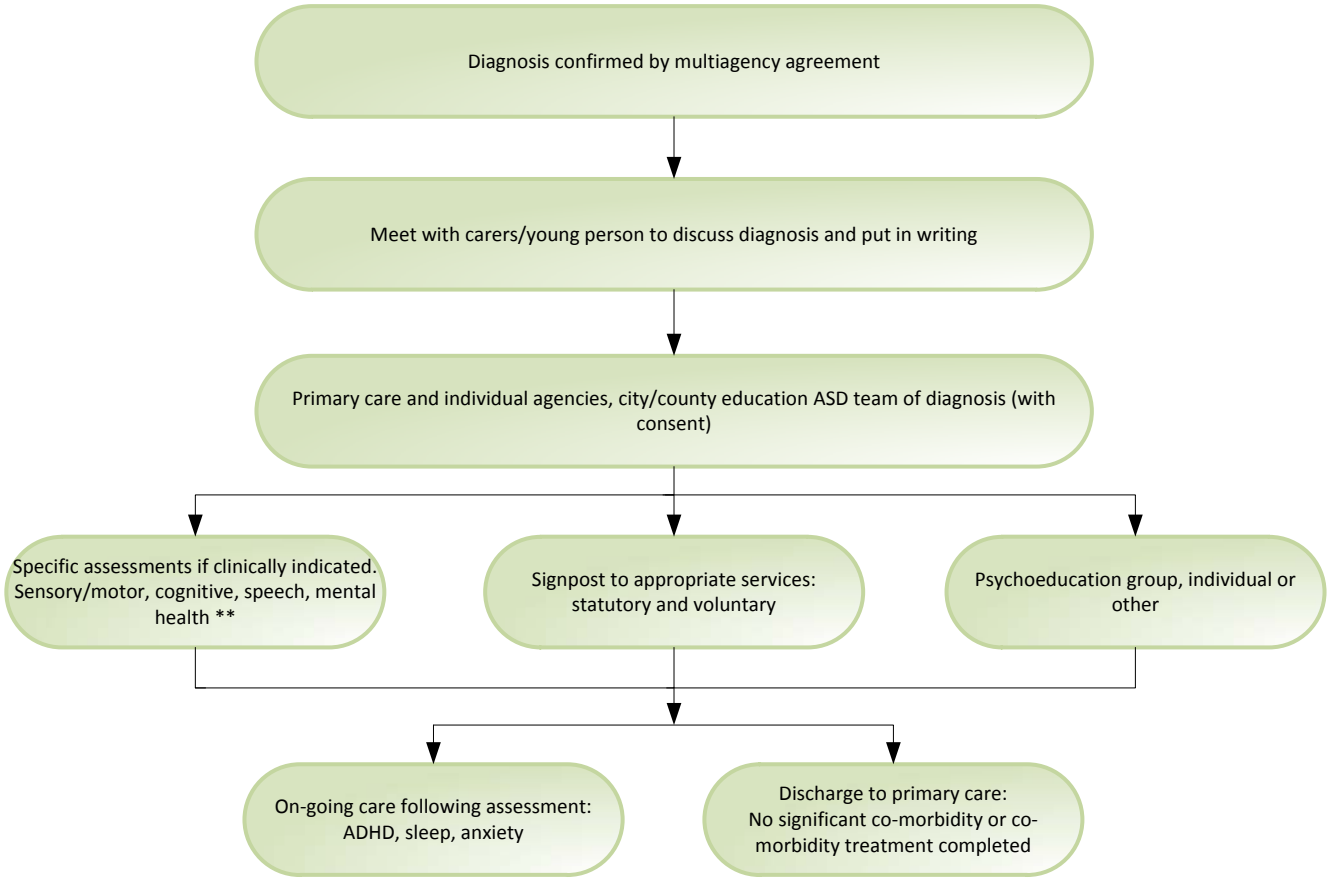
# Post Diagnosis Pathway




** OT not currently commissioned to provide sensory programmes for children with ASD

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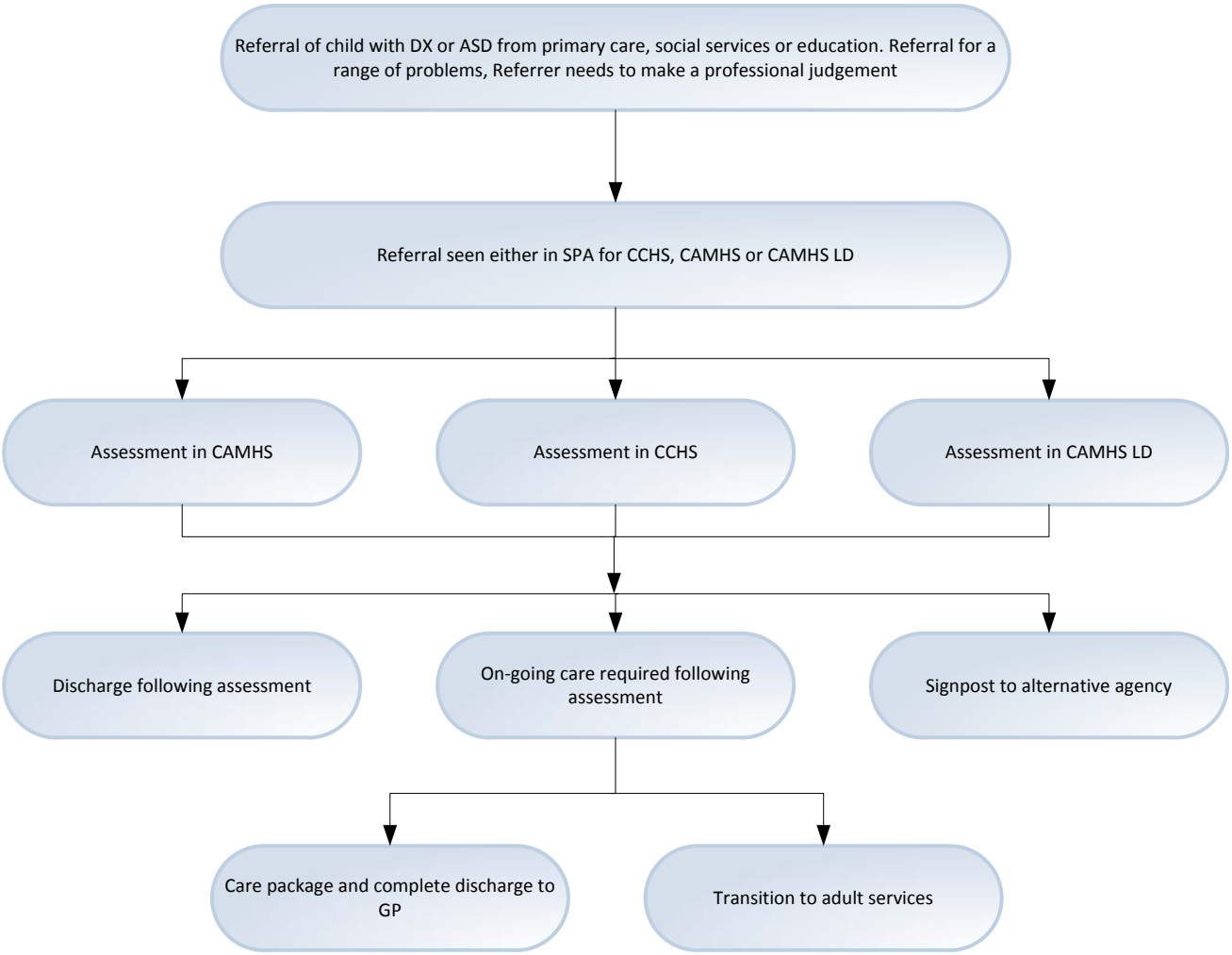
# Re-referral Pathway



# Autism Spectrum Disorder Pathway March 2009

**(amendments Version 6: 21.07.11)**

| Sign off of Original Document completed as below: | | | | |
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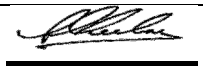
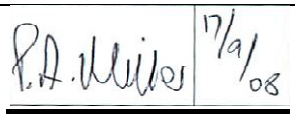
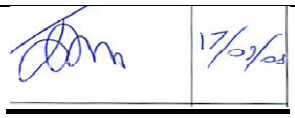
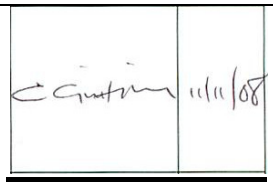
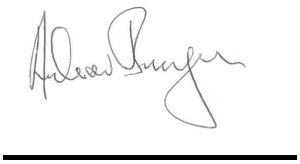
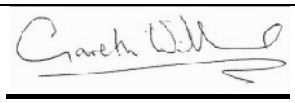
| **Logo** | **Organisation** | **CEO** | **Signature** | **Date** |
| Leicestershire Partnership NHS Trust | **Child & Adolescent Mental Health Service** | Antony Sheehan |  | Dec'08 |
| Leicester City NHS Community Health Service | **Children's Community Health Service** | Paul Miller |  | Sep '08 |
| NHS Leicester City | **Leicester City NHS Primary Care Trust** | Tim Rideout |  | Sep '08 |
| NHS Leicestershire County and Rutland | **Leicestershire County and Rutland NHS Primary Care Trust** | Catherine Griffiths |  | Nov '08 |
| Leicester City Council | **Leicester City Children and Young People's services** | Andrew Bunyan |  | Aug '08 |
| Leicestershire County Council | **Leicestershire Children and Young People's services** | Gareth Williams |  | Oct '08 |
| Rutland County Council | **Rutland Children and Young People's Services** | Carol Chambers |  | Dec '08 |

## Index



Version 6: Text was updated in 2011 following the ASD audit in 2010. Changes include some alterations to text and the flowchart. Also there are 3 ***NEW*** appendices. Speech and Language Therapy referral Guidelines (Appendix 6), Guidelines on the role of a Coordinator (Appendix 7) and Summary information for Parents/Carers in Appendix 8.

# Autism Spectrum Disorder Pathway

## Introduction

The purpose of this guidance is to describe expected practice in relation to children whose needs may fall within the Autism Spectrum Disorders (ASD) - 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/carers 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 following terms are used interchangeably in this document "identification" & "diagnosis" and "Autism", "ASD" & "Autism Spectrum Disorder".

## 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 within the Autism Spectrum Disorders. 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. It also makes 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/carers 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 parents/carers.

## The Importance of Parents/Carers

Parents/Carers are essential partners in the assessment process. They are also 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/carers 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/carers 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 9.
Stage 1: Initial concerns re. communication /social interaction & gathering information

- Health Practitioners in consultation with parents/carers 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 in partnership with parents/carers, 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). If a referral to CAMHS is felt appropriate then either the GP or an educational psychologist would need to be involved to make the referral.

- A professional who will be the coordinator for the child's assessment should be identified from the professionals involved with the family and child (this may be done as part of the CAF). The coordinator should be someone who is working closely with the family and can be self appointed (with the family's consent). Once the coordinator is identified then the other professionals and parents/carers should be informed (preferably in writing) by the coordinator. For further information on the coordinators role, see Appendix 7.

- The coordinator should support the family in involving the child or young person in the process.

Stage 2: Referral for Health Assessment

- Children with difficulties with social communication/ social interaction 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 to 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 additional health needs, (as outlined in parts a and b above), 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 parts a & b overleaf) 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 are concerns suggesting that the other service should be involved, (such as indicated in part a and b overleaf), 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 referral should be sent to the SPA for the other service clearly indicating that the request is for a SECOND OPINION. Please see * below
    iv. If after assessment it is felt that a joint assessment is needed with the other service, then a referral should be sent to the SPA for the other service clearly indicating that the request is for a JOINT assessment 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).

- If Speech and language therapy are not involved with a child, then referral to Speech and language therapy should be considered in accordance with SALT referral guidelines (see Appendix 6). Information on the guidelines for referral to SALT is available in Appendix 6 and there is also guidance available on the CCHS website for school aged children at: http://website.leicschildhealth.nhs.uk/Library/GuidelinesforSchoolAgeReferral.pdf . Schools must complete the initial screen (as per the CCHS website guidelines) prior to considering a referral to SALT

Stage 3: Comprehensive Assessment

- The coordinator 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 in a timely manner.

- The information gathered should include observations in, and/or information from, different settings and an early developmental history. It should also include information on strengths and interests.

- Multiagency liaison including all professionals and parents/carers (unless it is felt inappropriate for parents/carers to attend or they decline) 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 coordinator for the child. The diagnosis should be made by a minimum 2 professionals who are able to make a diagnosis from 2 different agencies. Currently the professionals able to make a diagnosis are clinical psychologist, educational psychologist, paediatrician or child and adolescent psychiatrist. Where possible the coordinator should be present at the meeting. The coordinator should also seek information from all the professionals involved who are unable to attend the meeting and where appropriate the child/young person.

- In the event that a multiagency meeting cannot be held within a reasonable time frame, then the coordinator should liaise with the other professionals to let them know who is involved and so enable the full gathering of information from all the different agencies involved (via reports or telephone). When professionals supply information via reports or telephone (rather than via a meeting), it is essential that the professionals view of whether there are difficulties (or not) with the child's social and communication skills, should be clearly indicated. The coordinator should inform the other professionals involved if there is any difference of opinion when they collate the information.

Stage 4: Outcome of Assessment

**Stage 4a: ASD IDENTIFIED**

- Once the professionals involved in the assessment are satisfied that any 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/carers at this meeting. The identification of an ASD should then be confirmed in writing to the parents/carers and all professionals. If the coordinator should need to change at this point, then parents/carers, child/young person and other professionals should be informed.

  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.

- A care plan is prepared and implemented along with an education plan where appropriate

- If the Educational Psychologist is involved then the Educational Psychologist should make a referral to Autism Outreach Service (AOS) for County children or to Learning and Autism Support Team (LAST) in the City. If there is no Educational Psychologist involved then the coordinator should inform AOS/LAST as appropriate.

**Stage 4b: ASD NOT IDENTIFIED**

- **ASD EXCLUDED**
  Once the professionals involved in the assessment are satisfied that any uncertainties have been resolved, and that an Autism Spectrum Disorder is NOT identified, then this should be confirmed in a face to face meeting with the parents/carers (if this has not already taken place at Stage 3). The strengths and difficulties of the child should be indicated and any alternative diagnosis given. The information should be confirmed in writing to the parents/carers and all professionals. Appropriate support should be suggested where indicated.

- **ASD NOT EXCLUDED**
  1. Where more time is required for assessment (such as for a child to develop, or for an intervention to be evaluated), then parents/carers should be informed verbally (and in writing) of what the next steps are and when the circumstances will be reviewed.

  2. Where there is uncertainty or disagreement within the group of professionals involved with the child as to the outcome, then the practitioners should seek a joint assessment or second opinion with CAMHS/CCHS. When uncertainty remains after a joint assessment or

second opinion with CAMHS/CCHS then the Autism Reference Group's opinion should be sought (as discussed below).

Stage 5: Transition

- Review of the care and educational plan on a multiagency basis should determine ongoing involvement with the child
- Protocols are currently being considered by the Adult Asperger's Planning Group to inform the progression to adult services for those with Autism Spectrum Disorders.

## Dealing with disagreements

- If after a joint assessment or second opinion from CAMHS/CCHS, there is still disagreement within the group of professionals involved with the child as to the outcome, then the practitioners should request a review of all of the evidence by the Autism Reference Group (see role of Autism Reference Group below)

- Where parents/carers or a young person disagrees 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/carers of the possible next steps, including consideration by the Autism Reference Group (see role of Autism Reference Group below)

## Role of the Autism Reference Group (ASG)

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. When the group meets to discuss disagreements the chair of the meeting is the parent representative (with support if required).

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

- Parent representative and member of Leicester National Autistic Society on 0116 291 6958 or the secretary to Dr Shawcross on 0116 225 2525.

## *Guidance for Multi Agency Professionals*

**Integrated Care Pathway for Autism Spectrum Disorders**

## *Leicester, Leicestershire and Rutland*

***The following should be read in conjunction with the text of the document and Appendix 4***

Start (0 months) — 6 months — 9 months — 1 year

### Stage 1: INITIAL CONCERNS Re. COMMUNICATION /SOCIAL INTERACTION AND GATHERING INFORMATION

Parental concerns or Professional concerns (with parental consent) directed to:

| GP/SW | SALT/HV | Early Years Setting/School |
|---|---|---|
| • Assesses<br>• Provides advice/intervention<br>• Refers to CAMHS/CCHS | • Assesses<br>• Provides advice /intervention / refers to other agencies (including CCHS) | • SENCo implements SEN Code of Practice<br>• Refers to Teacher Support Services &/or EP<br>• Refers to CCHS or EP may refer to CAMHS |

Professional involved advises parents/carers of Community, Voluntary & Independent support agencies. A coordinator for the family is identified (see text p 5 and Appendix 7)

### Stage 2: REFERRAL FOR HEALTH ASSESSMENT

(to consider and exclude any additional health needs or other diagnosis)

Notify GP if GP is not making referral themselves

CAMHS ↔ CCHS (& referral to SALT to be considered)

### Stage 3: COMPREHENSIVE ASSESSMENT

Supported by multi agency information

Parents and all the professionals involved with child contribute to the assessment

Whenever possible a multiagency meeting is held to share information. If this is not possible, then see text on page 6.

### Stage 4: OUTCOME OF ASSESSMENT

| Stage 4a: ASD IDENTIFIED | Stage 4b: ASD NOT IDENTIFIED | | |
|---|---|---|---|
| Diagnosis and information on ASD given to parent/carers in face to face meeting & confirmed in writing to parents/carers and all professionals.<br>Multi agency working with Child continues. A care plan is prepared & implemented, along with an education plan where appropriate.<br>Parents given information about relevant ASD training, locally available intervention approaches (e.g. Early Bird & Early Bird Plus) & support agencies (Community, Voluntary and Independent) | **ASD EXCLUDED** | **ASD NOT EXCLUDED** | |
| | Alternatives explored and appropriate support given | Further information needed :<br><br>date for review set | Need 2nd opinion or joint assessment:<br><br>Referral to CAMHS/ CCHS / (see text in document) |
| | **DEALING WITH DISAGREEMENTS** | | |
| | No multiagency consensus for ASD<br>↓<br>Case discussed at multi agency Autism Reference Group | | |

MULTI AGENCY WORKING CONTINUES WITH THE CHILD AND FAMILY

### Stage 5: TRANSITION

## 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. The Medical Research Council review of Autism research (see overleaf) 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/carers. 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 (e.g. 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 cannot 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 (e.g. 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 (e.g. 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 cannot 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.

There two types of diagnostic criteria used. These are based on the Triad of impairment.

There is the **Diagnostic and statistical manual of mental disorders: DSM-IV-TR**. This is produced by the American Psychiatric Association and can be viewed either via a subscription to Psychiatry on line at http://www.psychiatryonline.com/ or purchased/ viewed at your Library (ISBN 978-0-89042-024-9 ). For copy write reasons the Diagnostic and statistical manual of mental disorders: DSM-IV-TR criteria cannot be viewed on this document.

There are also the diagnostic criteria from the **ICD-10 Classification of Mental and Behavioural Disorders Diagnostic criteria** for research by the World Health Organization Geneva 1993. The World Health Organisation has kindly given permission for the section on Childhood Autism (Section F84.0 from bottom page 180- top page 182) to be reproduced in this document. This document and other WHO documents can also be viewed on the WHO website at http://www.who.int/classifications/icd

**F84 PERVASIVE DEVELOPMENTAL DISORDERS from ICD-10 1993 by WHO**

**F84.0 Childhood autism**

**A.** Presence of abnormal or impaired development before the age of three years, in at least one out of the following areas:

(1) receptive or expressive language as used in social communication;
(2) the development of selective social attachments or of reciprocal social interaction;
(3) functional or symbolic play.

**B.** Qualitative abnormalities in reciprocal social interaction, manifest in at least one of the following areas:

(1) failure adequately to use eye-to-eye gaze, facial expression, body posture and gesture to regulate social interaction;
(2) failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
(3) A lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context, or a weak integration of social, emotional and communicative behaviours.

**C.** Qualitative abnormalities in communication, manifest in at least two of the following areas:

(1) a delay in, or total lack of development of spoken language that is not accompanied by an attempt to compensate through the use of gesture or mime as alternative modes of communication (often preceded by a lack of communicative babbling);
(2) relative failure to initiate or sustain conversational interchange (at whatever level of language skills are present) in which there is reciprocal to and from responsiveness to the communications of the other person;
(3) stereotyped and repetitive use of language or idiosyncratic use of words or phrases;
(4) abnormalities in pitch, stress, rate, rhythm and intonation of speech;

**D.** Restricted, repetitive, and stereotyped patterns of behaviour, interests and activities, manifest in at least two of the following areas:

(1) an encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature although not abnormal in their content or focus.
(2) apparently compulsive adherence to specific, non-functional, routines or rituals;
(3) stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting, or complex whole body movements;
(4) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration that they generate);
(5) distress over changes in small, non-functional, details of the environment.

**E.** The clinical picture is not attributable to the other varieties of pervasive developmental disorder; specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioural disorder; schizophrenia (F20) of unusually early onset; and Rett's syndrome (F84.2).

**F84.1 Atypical autism**

**A.** Presence of abnormal or impaired development at or after age three years (criteria as for autism except for age of manifestation).

**B.** Qualitative abnormalities in reciprocal social interaction or in communication, or restricted, repetitive and stereotyped patterns of behaviour, interests and activities (criteria as for autism except that it is not necessary to meet the criteria in terms of number of areas of abnormality).

**C**. The disorder does not meet the diagnostic criteria for autism (F84.0).
Autism may be atypical in either age of onset (F84.11) or phenomenology (84.12), these two types being differentiated with a fifth character for research purposes. Syndromes that are atypical in both respects should be coded F84.12.

## Appendix 4 – Glossary

| | |
|---|---|
| **ASD** | Autism Spectrum Disorder |
| **ARG** | Autism Reference Group |
| **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 |
| **SALT** | 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) |
| Mrs V Brown # | Clinical Lead Speech and Language Therapist for Children with a Complex Communication Disorder (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) |
| Mrs R Leavesley | Speech and Language Therapist (CCHS) |
| 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 |

Revision for Version 6 : May 2011 included the following people and those above marked #:

| | |
|---|---|
| Dr Clare Boorn | Senior Practitioner Educational Psychologist Leicestershire County Council |
| Davinder-Singh Dhesi | Senior Educational Psychologist Leicester City Council |
| Jane Hall | Parent Representative and member of parent carer council and ARG |

## Appendix 6: Speech and Language Therapy Referral Guidelines

The Speech and Language Therapy Service meets the needs of children or young people with significant delay and/or persisting needs in the areas of speech, language, communication and social interaction.

**Referral Criteria:**

Referrals are accepted for children (0-16 years) and young people (16-19 years in statutory education, such as special school provision) with the following**:**

- Speech, language and communication difficulties which are severely restricting social interaction
- Difficulties in social communication skills which are significantly affecting an ability to access the curriculum
  e.g. unable to take part in small group discussions
  e.g. unable to relate to others in small groups and unstructured opportunities
  e.g. difficulties using language for social interaction

**Referrals not accepted:**

- Where there are no speech and language therapy needs or social interaction difficulties identified from the referral, and in addition to this, the referrer is seeking support with a diagnosis from the service as part of the ASD Pathway
- Where the child's speech, language, communication and interaction skills could be met effectively within the school and/ or other agencies e.g. Autism Outreach
- For young people aged 16-19 years who are not in statutory education
- Where the child has complex needs in the areas of social interaction and communication, and there may be associated behaviours with a psychiatric and/or emotional disturbance, which may be more suitably assessed by CAMHS
- When the child's speech, language, communication and interaction skills are developing in line with his/her general development

Please refer to the ASD Pathway Flowchart on page 9 for further assistance

**References:**

RCSLT (2006) Communicating Quality 3: RCSLT, London

## Appendix 7 Guidelines on the role of a Coordinator

The coordinator is someone who can assist the family to go through the ASD pathway process.
Some parents/carers may find it helpful to have their child's preschool key worker or school teacher/SENCo acting as the coordinator. The coordinator does not make the "ultimate decision" about the problems that a child has as those decision are made jointly by all the professionals who are involved with a child for whom there is a query about autistic spectrum disorder.

The coordinator for the child's assessment via the ASD Pathway should be identified out of all the professionals involved with the family and child (this may be done as part of the CAF). The coordinator should be someone who is working closely with the family and can be self appointed (with the family's consent). Once the coordinator is identified then the other professionals and parents/carers should be informed (preferably in writing) by the coordinator.

- The coordinator should support the family in involving the child or young person in the process.

- The coordinator should consult all other agencies involved with the child, with parental permission, as part of the assessment process as per Stage 3: Comprehensive Assessment on page 6

- The coordinator for the child should assist in the organisation of a multiagency meeting as per part 4 of Stage 3: Comprehensive Assessment on page 6.

- Where possible the coordinator should be present at the meeting where a diagnosis is to be made. The coordinator should also seek information from all the professionals involved who are unable to attend the meeting and where appropriate the child/young person.

- If a coordinator is of the opinion that a multiagency meeting cannot be held within a reasonable time frame, then the coordinator should liaise with the other professionals to let them know who is involved and so enable the full gathering of information from all the different agencies involved (via reports or telephone). The coordinator should inform the other professionals involved if there is any difference of opinion when they collate the information. The coordinator should maintain a current record of the professionals involved.

- Once the coordinator is made aware that all the professionals involved in the assessment are satisfied that any uncertainties have been resolved and that ASD is identified or excluded, this should be confirmed by the/a professional(s) in a face to face meeting with the parents/carers.

- A different coordinator can be appointed at any stage with parental consent.

## Appendix 8 – Summary Information for Parents/Carers (also see flow chart on page 10 and Appendix 4)

**1. What to do if as a parent you have concerns that your child has difficulties with their communication/ behaviour**

*For a preschool child* -talk to your Health visitor, Nursery teacher, SALT or GP

*For a school aged child*- talk to your school teacher, School SENCo, school nurse or GP

**2. What should happen next?**

The professional you have spoken to will assess your child and decide if a period of observation is needed or if they need to make a referral to someone else. They will let you know what they decide. The flow chart on page 10 is a summary of what happens.

**3. What does a coordinator do and can I choose one?**

The coordinator is someone who is involved with your child and who can help you as you go through this process. You can ask if a particular person could be the coordinator. Some parents/carers find it helpful to have their child's preschool key worker or school teacher/SENCo acting as the coordinator. The coordinator does not make the "ultimate decision" about the problems that your child has as that decision is made jointly by all the professionals who are involved with your child.

**4. What should I do if nothing seems to be happening?**

*If you have a coordinator*, then talk to the coordinator who can help you decide what to do next.

*If you do not have a coordinator*, then talk with one of the professionals involved with your child. It may be that the professionals have put various strategies in place and are wanting to wait to assess the effect of them. It is important not to get lots of people involved if further simple strategies will help. However, if after speaking to the professional you still feel that further people need to be involved then discuss this with the professional or their manager. If you are still not happy then speak to one of the other professionals involved with your child (as indicated in question 1 above).

*Alternatively* you can seek assistance from the Parents and Carer's council see question 8.

**5. How long should the whole process take?**

How long the process takes varies from child to child. On average it is 6 months to a year from first concerns being raised by someone. Generally the process is quicker the younger your child is and the more significant their difficulties are. The process usually takes longer for older junior/ senior school children as many factors have to be considered.

It is important that everyone involved with your child should provide information to contribute to any decision about whether or not your child has or does not have an Autism Spectrum Disorder. In some cases children need to be seen several times and several multiagency meetings are held before it is clear what the difficulties are. Deciding too quickly that your child does have an Autism Spectrum Disorder (when they have *other difficulties*) or *does not have* an Autism Spectrum Disorder (when they *do*) is not helpful for you or your child.

However, it is also not helpful if everyone agrees with the difficulties but the professionals have not met/spoken to discuss. If this is the situation then see the answer to question 4 above.

**6. What can I do if I am confused by what I am being told or what is happening?**
Talk to your coordinator or another professional involved with your child and tell them that you are confused. It may be helpful to bring along someone else to a discussion so that you can both talk together about the appointment later.

If you are confused but do not want to talk to your coordinator or the professionals involved then you could contact one of the organisations listed in question 8 below.

**7. How can I get a second opinion?**
Ask your coordinator about this or the professionals involved if you can have a second opinion. If you are seeing a Community Paediatrician (from CCHS) then you can be referred to CAMHS for a second opinion or vice versa. You can ask PALS (Patient Liaison Service) to assist you with this if you wish via telephoning 0116 295 7011 for city children. If you live in the county then telephone 01455 441971/ 01509 564444 or e-mail pals@lcr.nhs.uk

**8. Who else can help me?**

**PALS (Patient Liaison Service.** PALS offer help or advice about healthcare in ***the NHS***. You can contact your local patient advice and liaison service (PALS) if you live in the City via telephoning 0116 295 7011. If you live in the County/Rutland then telephone 01455 441971/ 01509 564444 or e-mail pals@lcr.nhs.uk

**Parent Partnership** is a confidential and impartial service that supports families who have children with ***Special Educational Needs***. They support families of children and young people aged 0 to 19 years with any educational issues. Children do not need to have a statement of special educational need or a medical diagnosis of disability.
For children attending City Schools/preschools contact 0116 257 5027.
For children attending County Schools/preschools contact 0116 2752097 or
Email Address: parent-partnership-service@leics.gov.uk
For children in Rutland, the Parent Partnership Service is delivered via Rutland's Citizen's Advice Bureau at 56 High Street, Oakham, Rutland LE15 6AL.

**Menphys SOS** is a Special Outreach Service that helps children and young people (aged 0 – 19) with addition needs and their families in a variety of ways. This includes signposting families to appropriate and relevant services, co-coordinating the care of children with complex health needs and providing support.
Contact:- Menphys SOS 01455 899111, 01664 483315 or 0116 288 5353

**Parent & Carers Council** help, support, signpost and inform Parents/Carers over any issues they may have relating to services provided by all children & young people's services, including services provided by health.
Contact:- Parent & Carer's Council – Sue on 07968 857598, Jane on 07870 688973
or visit the website at http://parentcarercouncil.co.uk/SupportGroups.aspx

# ASD Diagnosis Health Care Pathway
# Guidance Notes

## Box C

Moderate and severe LD in health terms ( equivalent to ICD 10 coding for moderate mental retardation F71 and Severe MR F72, Profound MR F73) – assessed clinically as a child or young person functioning globally below half their chronological age ( daily living skills, communication skills and social skills). If there is an IQ it would be all those functioning below IQ of 50.

This should not be confused with the educational term 'learning difficulties' and indeed MLD as an educational term is not helpful in trying to decide the severity of childs learning disability as it may be used due to the co-morbidities such as ASD or ADHD.