

Date: 30 May 2012

*Work is currently taking place to review and update this pathway*

MULTI-AGENCY PATHWAY FOR IDENTIFYING AND  
SUPPORTING CHILDREN AND YOUNG PEOPLE WITH  
AUTISTIC SPECTRUM DISORDERS

**SCHOOL-AGE CHILDREN &  
PRE-SCHOOL CHILDREN IN  
MAINTAINED EARLY YEARS  
SETTINGS**

DERBYSHIRE COUNTY  
2012

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## **INTRODUCTION**

1. This guidance describes expected practice in relation to children and young people whose needs may fall on the autism spectrum. It focuses particularly on the importance of joint working between professionals when an Autistic Spectrum Disorder is suspected, and the need to put in place appropriate support for the child/family before a diagnosis is made.
2. All relevant agencies within Derbyshire County, which employ professionals involved in making a diagnosis or in supporting children and young people with Autistic Spectrum Disorders, have agreed that this pathway will be followed<sup>1</sup>.
3. Many children and young people with ASD will also have other conditions or needs. In particular, people with ASD are more likely to have a learning disability, epilepsy or Attention Deficit Hyperactivity Disorder (ADHD). They are also more likely to develop mental health problems at some stage. This pathway sets out good practice in supporting children and young people with ASD, whether or not they also have other conditions or needs. Clearly, it is important that children's needs are assessed in a holistic way.

### **Terminology**

4. This document refers to 'Autistic Spectrum Disorder' (ASD) which is the accepted diagnostic term. We are aware that some young people and parents/carers prefer alternatives, such as 'Autistic Spectrum Condition' or 'autism'.

### **Why is this pathway being developed now?**

5. A 'Task and Finish' Group of professionals from a wide range of agencies met during 2010/2011, and identified the need for a consistent, Derbyshire-wide pathway for identifying and supporting children and young people with Autistic Spectrum Disorders. In consultation with parents and young people and schools during 2011, there was strong support for better multi-agency working, early intervention and a clear pathway to get a diagnosis and access to services and support.

### **National context**

6. The National Service Framework for Children, Young People and Maternity Services (Department of Health 2004) set out the need for specialist services for children with ASD to be provided in a seamless fashion as close to the child's locality as possible. It stressed the importance of multidisciplinary and multi-agency working to meet the child's needs effectively and promptly.

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<sup>1</sup> With the exception of Glossop, where a different process is in place – see paragraph 38.

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7. 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 Autistic Spectrum Disorders. The National Autism Plan sets out best practice in diagnostic assessment.

8. The National Institute for Clinical Excellence (NICE) published guidelines on the assessment and diagnosis of children with Autistic Spectrum Disorders in 2011. The guidance recommends that a local multi-agency strategy group is established in each area, and a lead professional who will be responsible for the autism pathway for recognition, referral and diagnosis. It recommends that a multi-disciplinary 'autism team' is set up in each area with core membership including a Paediatrician and/or child and adolescent psychiatrist; a speech and language therapist and a clinical or educational psychologist. The guidance recommends a single point of referral for access to the autism team, and that there should be a 'case co-ordinator' for every child or young person who is to have an assessment.

### **Outcomes**

9. The focus should be on identifying the outcomes which it is hoped to achieve for each individual child/young person, and planning the strategies and support which need to be put in place to achieve them. This should be done in a person-centred way, which takes account of the young person's thoughts, feelings and wishes and involves parents/carers fully. It should be clear how and when strategies and/or support will be reviewed to see if they are working.

### **The role of parents/carers**

10. Parents and carers know their children best. Parents and carers must be treated as equal partners at every stage; their concerns must be listened to and they must be treated with respect. It is important that all parents/carers understand the pathway; that they not only understand what strategies and support are being put in place to support their child but can inform and shape those strategies. Where specific strategies are being used successfully at nursery or at school, parents and carers should be helped to test these strategies within the home environment as well.

### **Glossary**

ASD – Autistic Spectrum Disorder

EHA – Early Help Assessment

LP – Lead Professional

SEN – Special Educational Needs

GDA – General Development Assessment

SLT – Speech and Language Therapist

EP – Education Psychology

CAMHS – Child and Adolescent Mental Health Service

HV – Health Visitor

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## **THE DERBYSHIRE PATHWAY FOR ASSESSMENT, SUPPORT AND DIAGNOSIS**

11. This section should be read alongside the Flowchart on page 10.

### **Stage 1: Concerns about a child's development, communication or social interaction identified and collated**

12. Stage 1 of the pathway should be followed wherever there are concerns about a child's development, communication or social interaction. It is not specific to children with an Autistic Spectrum Disorder. The presentation of autism can be very similar to other developmental disorders e.g. Attention Deficit Hyperactivity Disorder or learning disability. Only qualified professionals can make a diagnosis – in the early stages of the pathway, it will not be certain that any child has ASD. It is very important that professionals do not suggest a possible diagnosis to the family at this stage.

13. Anyone – for example parents/carers, school nurse - who is concerned about a child's development, communication or social interaction should make their concern known to the child's school/setting **or** to the child's local multi-agency team (for example, where a child is excluded from school, home-educated or otherwise not attending school).

14. The school/setting or multi-agency team will then immediately initiate a Early Help Assessment (EHA), pulling together a Team Around the Child. They will draw on specialist advice and support where appropriate from the relevant services, e.g. Educational Psychology or other services as appropriate. As part of the EHA, a lead professional will be identified to work with the child and their family. The school/setting will make sure that the SEND Code of Practice is initiated so the child or young person can get appropriate support pending further assessment of their needs. Support and appropriate strategies should be put in place from the outset, where they are needed. The focus should be on identifying the outcomes which it is hoped to achieve, and planning the support which need to be put in place to achieve them in a person-centred way, which takes account of the young person's thoughts, feelings and wishes and involves parents/carers fully. It should be clear how and when strategies and/or support will be reviewed to see if they are working.

**No child, young person or their family should have to wait until a diagnosis has been made before being able to access services and support.**

15. The expectation is that for 13 weeks (i.e. 2 Derbyshire terms) the school/setting and/or multi-agency team will record their initial concerns about the child and what actions/strategies they will try to meet the child's needs, using the template developed by the Educational Psychology service at Appendix 1.

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16. If concerns remain significant, despite intervention over 13 weeks, and they are suggestive of ASD or another developmental disorder, the school/setting or multi-agency team will make a referral for a General Developmental Assessment (stage 2 of the pathway). **IMPORTANT:**

- **If a child appears to be losing skills they have already achieved e.g. language skills it is vital that they are referred to a Paediatrician immediately without waiting for 13 weeks;**
- **If there is a risk of significant harm to the child or to others, at a minimum advice should be taken from Social Care without waiting 13 weeks.**

#### Role of General Practitioners (GPs) and Speech and Language Therapists:

17. Usually, either the school/setting or the multi-agency team will refer for a General Developmental Assessment (GDA). However, GPs already refer children for a GDA, and will continue to be able to do so in the future. Likewise, Speech and Language Therapists will refer children for a GDA if it is clear that they need one. Referrals by GPs and Speech and Language Therapists will be made immediately, i.e. without waiting 13 weeks. As good practice GPs and Speech and Language Therapists should also inform the child's school/setting or multi-agency team when they make a referral, to ensure that they can initiate a EHA/Team Around the Child and the SEN Code of Practice.

#### Role of Health Visitors:

18. Health Visitors see all children routinely at 30 months, when parents/carers are asked to complete an 'Ages and Stages Questionnaire - Social and Emotional' (ASQ-SE). Health Visitors do not routinely see children at 18 months/24 months, but will do so where there are concerns about a child's development. In these circumstances they will also ask the parents/carers to complete the appropriate ASQ-SE.

19. If the results of an ASQ-SE are suggestive of a social communication disorder, the Health Visitor will provide advice/support to the family and consider whether to make an immediate referral for a General Development Assessment. The Health Visitor should inform the child's setting or multi-agency team when they make a referral, and refer to the Early Years Panel, to ensure that the SEN Code of Practice can be initiated and appropriate support be put in place.

#### **Stage 2: General Development Assessment**

20. Like Stage 1 of the pathway, Stage 2 applies to all children where there are concerns about their development, communication or social interaction. It is not specific to children with ASD.

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21. Stage 2 of the pathway is referral for a General Development Assessment, to consider any additional health needs and rule out other conditions. An EHA and referral letter will be submitted as the basis for a referral. The letter should explain why the referral is being made and what the issues are. The GDA will always be carried out by a Paediatrician. In north Derbyshire, referrals will usually be made to the Child Development Centre at Chesterfield Royal Hospital Foundation Trust. Referrals for High Peak will go to Buxton Health Centre<sup>2</sup>. In southern Derbyshire, referrals will be made to the Single Point of Access for specialist health services.

### **Stage 3: ASD Specific Assessment**

22. If the General Development Assessment concludes that ASD is likely or possible, the child or young person will have an ASD specific assessment. It is the role of the Paediatrician to make sure that a professional with the right skills and experience is assigned to lead each ASD-specific assessment. It is then the responsibility of that professional to ensure that families are informed about the process and timescales and can contribute to the assessment; that the agreed pathway is followed; that appropriate evidence is gathered together (making use of any existing assessments) and that, with families' consent, information about the outcome is shared with other services so they can contribute to planning for the young person and their family.

23. The ASD specific assessment will usually be led by a Paediatrician, who will request specific input from other services e.g. Clinical Psychology and Speech and Language Therapy. If the child's presentation is complex, or more than one condition is suspected, the Paediatrician may organise a formal Multi-Disciplinary Assessment.

24. In south Derbyshire, if the child's presentation is complex or the Paediatrician needs a second opinion they may make a referral to the multi-disciplinary Social Communication Disorders Assessment Service (SCODAS). If the child is under 8 years, they will be seen first by the ASD Specialist Consultant Paediatrician. If the child is over 8 years, they will be seen first by Clinical Psychology.

25. The ASD-specific assessment will always bring together:

- an ASD specific developmental history;
- observations of the child/young person across a range of different settings (e.g. home / school / clubs or activities)
- an ASD-specific speech and language assessment;
- a medical assessment.

26. The ASD-specific assessment will draw upon existing assessments and histories wherever possible, by gathering together information from all relevant services/professionals. It should not duplicate assessments which

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<sup>2</sup> See para38 for the arrangements for children who are registered with GPs in Glossop

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have already been completed. It will include a cognitive assessment where appropriate.

27. The ASD-specific assessment will always involve at least 2 professionals from different disciplines who are experienced in assessment and diagnosis of ASDs. It will also involve at least one professional who is trained in the use of ADI-R, 3Di or DISCO - tools for taking ASD-specific development histories. These need not be used in every assessment, although they may improve reliability of diagnosis where there is doubt. Over time, the intention is to move towards greater consistency across all services as to which assessment tools are used.

28. Stage 3.a. of the pathway involves a multi-agency meeting to agree the diagnosis. In practice, sometimes the diagnosis will be straightforward and it will not be necessary to have a meeting providing that all of the professionals involved agree, and all the observations/evidence point towards the same conclusion. Where there is disagreement, or if the diagnosis is not straightforward, a meeting should be held.

#### **Stage 4: Feedback and Support Planning**

29. Following the multi-agency meeting, feedback must be given to parents/carers face-to-face by the most appropriate person. Parents/carers must not be told their child's diagnosis over the 'phone or in writing. Parents/carers should be given a written report at the meeting about the outcome of the ASD-specific assessment and the diagnosis. The written report should include a profile of the child or young person's strengths, skills, impairments and needs, taking into account family and educational context. The family should be told what will happen next, and given some general information and contacts about ASDs. The diagnosis should also be communicated to the child's lead professional. The person who leads the ASD-specific assessment is responsible for making sure that this happens.

30. Within 4 weeks of the diagnosis, the child's lead professional should arrange a Team Around the Child meeting to review and update the child's support plan. This meeting should involve the parents/carers, school or setting and specialist services as appropriate (e.g. Autism Outreach Team; Educational Psychology; Clinical Psychology). Wherever possible, it should involve the child or young person. If this is not possible or would not be appropriate, work should be done with the child/young person before the meeting to establish what's important to them.

31. The support plan should be developed in a person-centred way, which takes account of the young person's thoughts, feelings and wishes and involves parents/carers fully. It should describe the strategies and/or provision which is going to be put in place and the outcomes which it is hoped to achieve. It should set out how and when these strategies and/or support will be reviewed to see if they are working.

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32. The plan should be clear about what ongoing support will be needed. Some children and young people with ASD will need a high level of support; others may need very little. As a minimum, there needs to be a lead person ('lead professional') who will be responsible for checking periodically that things are going ok and any strategies that have been put in place are working (or working together effectively, where a child/family is receiving support from a number of teams/professionals or the family/school are getting input from different services). This could be a Special Educational Needs Co-ordinator; Family Resource Worker; Teaching Assistant; Multi-Agency Team member; social worker; health professional: it should be the most appropriate person to take on that role.

33. Whoever takes on the lead professional role, it remains the responsibility of each service working with a child to make sure they are clear about the outcomes they are aiming to achieve, and to regularly review whether the support which is being provided is achieving results.

34. The lead professional is responsible for making sure that there is an overall plan to achieve a smooth transition into adult life/adult services for young people at the age of 18, in line with the Derbyshire Preparing for Adulthood Pathway.

35. Appendix 2 gives details of the services which can provide support for young people with ASD, including referrals/eligibility criteria.

#### Role of CAMHS in assessment/diagnosis:

36. Where older children are referred to CAMHS with co-existing mental health problems, or where CAMHS is already working with a child, CAMHS will lead an ASD-specific assessment to avoid repeated referrals between agencies (and to minimise waiting times for children and their families). ASD-specific assessments which are carried out by CAMHS must comply with NICE guidelines and meet all of the same requirements as those carried out by other services. They should involve at least one professional who is medically trained, i.e. a Paediatrician or Psychiatrist.

#### The Children's Autism Co-ordinating Group:

37. A Children's Autism Co-ordinating Group will monitor implementation of this pathway. The group will aim to:

- improve early recognition of autism by raising awareness of the signs and symptoms through multi-agency training;
- make sure the relevant professionals (health, education, social care, voluntary sector) are aware of the pathway and how to access services;
- support a smooth transition to adult services for young people with ASD;

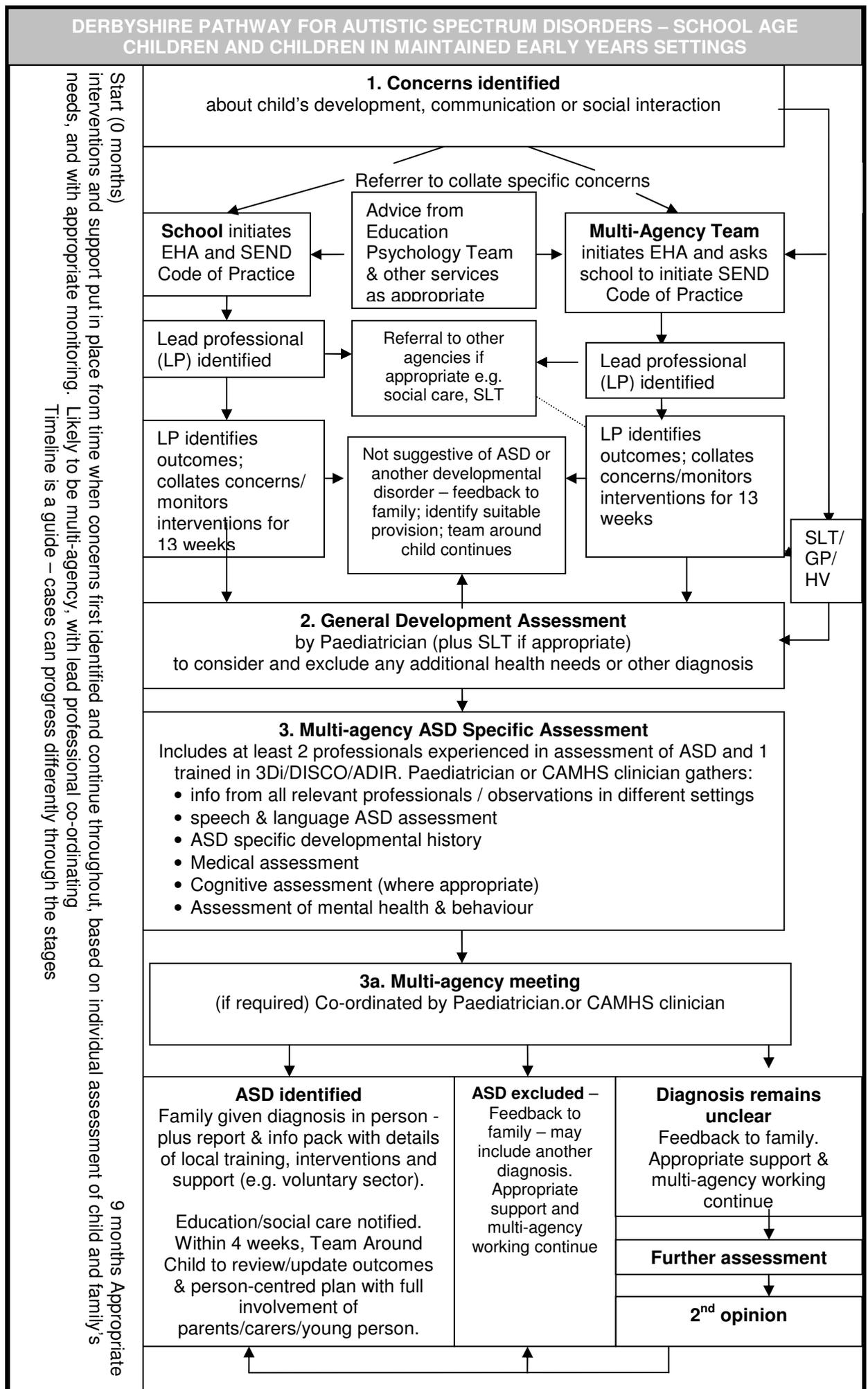
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- ensure data collection and audit of the pathway and outcomes for children and young people with ASD takes place
- develop standardised information for young people and parents/carers about the services and support which is available
- make sure that children with ASD can access appropriate therapies and interventions on the basis of need, and not according to where they live or which services they are engaged with

Children and Young People who are registered with Glossop GPs:

38. In Tameside and Glossop there is an Integrated Disabled Children's Service which acts as the single point of referral and organises all assessments and diagnosis of Autistic Spectrum Disorders. Children who live in the County of Derbyshire, but are registered with a Tameside and Glossop GP, will be referred to this service for assessment/diagnosis. In all other respects they will follow the Derbyshire pathway and will have the same access to all Derbyshire County Education and Social Care services.

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## **APPENDIX 1: TEMPLATE FOR SCHOOLS/SETTINGS OR MULTI-AGENCY TEAMS TO RECORD CONCERNS**

(Note - This may also be known as the 'Pre-Referral Action' form by schools and settings)

Children with autism typically have difficulties in the following areas:

- Language and social communication
- Interaction and relationships
- Rigidity and lack of flexibility
- Sensory processing

Further information about these areas of difficulty is available electronically in *The Derbyshire File for Autism Friendly Schools*.

Use the table below to identify your initial concerns in these areas and plan interventions to meet the child's needs. Keeping a diary over a period of a full week can be a good way of helping to identify what the concerns are – choose a week when there is nothing unusual happening at school or at home. Ideally, you will evaluate the outcomes of any actions or interventions tried over a period of time to see if anything has changed. This information can be submitted for consideration along with your referral form.

<b>Area of difficulty</b>	<b>Initial concerns</b>	<b>Actions/intervention</b>	<b>Outcome</b>
<b>Language and social communication</b>			
<b>Interaction and relationships</b>			
<b>Rigidity and lack of flexibility</b>			
<b>Sensory processing</b>			

Before making a referral, schools should consult resources available and work to develop an appropriate and graduated response, as suggested in Derbyshire's descriptors of SEN.