

Diagnosis and Identification of

AUTISTIC SPECTRUM DISORDERS

A Guide for Parents and Carers



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***Diagnosis and Identification of Children and Young People
on the
Autism Spectrum:***

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1. Introduction

In recent years the number of children identified as being within the autism spectrum has risen steeply in Leicestershire. There has also been a steady fall in the age at which diagnosis is being made. Despite improvements in practice, the period before and during the process of diagnosis can be frustrating and distressing. Parents often know, or at least suspect, that there is something that is 'not right' about their child's development - and they want to know what that 'something' is.

This leaflet aims to do a number of things:

- To describe what's involved in the diagnosis of children and young people within the autism spectrum
- To explain some of the issues and controversies that surround the whole process of identification
- To answer some of the questions that are often asked

We have tried to cut jargon down to a minimum and keep the leaflet to a manageable length. This means that some complex issues have had to be simplified and some topics have had to be left out altogether. By organising the leaflet around key questions we hope that we have made it easier for you to find the information that is particularly relevant to your circumstances. If you do need additional information it may be helpful to contact the National Autistic Society on 0845 070 4004 and www.nas.org.uk or the Leicestershire branch of the National Autistic Society on 0116 291 6958.

2. *What is the autism spectrum?*

The National Autistic Society defines the autism spectrum as "a complex life long developmental disability that affects the way a person communicates and relates to people around them". There are a number of important points that you need to be aware of:

- There is now general agreement about the 'core' difficulties that make up autism. These are often referred to as the 'triad of impairments' and consist of problems in terms of: social interaction; communication (particularly the way that communication skills are used); inflexibility of thinking and behaviour (including limited imagination and repetitive behaviour). Significant problems in each of these areas have to be present for autism to be identified.
- The difficulties in the 3 areas can actually show themselves in a very wide range of different ways. How they do this will depend on the overall severity of the autistic difficulties, what other difficulties the child experiences (particularly in terms of learning), and the child's age. It's also important to stress that the severity of the difficulties may vary across the 3 areas of the triad.
- The pattern of difficulty may well change over time and some aspects of the pattern are more obvious at some stages of the child's development than at others. Some problems may not show up until the child reaches a certain stage of development. Others may get less obvious as the child learns new skills that help him/her to cope and compensate for some of the difficulties.

It is very common for difficulties within the autism spectrum to occur along side other problems. Learning difficulties are particularly common, although very able people can have a diagnosis of difficulties within the autism spectrum

- It is also very important to stress that all people within the autism spectrum have their own personalities. They will also have had different experiences and opportunities to learn, as they have grown up.

3. Why do so many different labels seem to be used?

You are likely to come across a whole range of different words used to describe children or young people within the autism spectrum. Sometimes it seems like different words are being used to describe the same type of difficulty—sometimes the words seem to be referring to completely different types of children. This apparent muddle reflects the fact that there is still a lot of uncertainty and controversy about whether there are different types, or ‘sub-groups’, of the autism spectrum—and how the different types relate to each other. These points may help you to make some sense of this confusion:

- The term ‘autism spectrum’ is in increasingly common use, and is beginning to replace the term ‘autistic spectrum disorder’. This may be because people with a diagnosis may not see it as being a ‘disorder’ at all as it brings with it many strengths and different ways of thinking. These terms are used to refer to the whole family of overlapping or related conditions—all involving the triad of impairments
- The 2 most widely known systems of diagnostic criteria are usually known by the sets of initials DSM-IV and ICD-10. Neither of these systems actually uses the term autistic spectrum disorder at all. They try to distinguish the different types of autistic spectrum disorder and use similar (but not identical) labels for these. They use terms such as childhood autism, Asperger syndrome, atypical autism and Pervasive Developmental Disorder. These are currently under review. To add to the complication, other terms are also used by writers and researchers (for example, ‘high functioning autism’)
- The term Asperger syndrome tends to be used to refer to more subtle forms of autism, usually when these are combined with average or above average levels of ability. There may be serious problems with the social aspects of communication. Difficulties with speech and language are usually the least noticeable feature.
- For practical purposes, what is most important is to decide whether or not a child has difficulties within the autism spectrum. Eventually it may be shown that there are a number of distinct and separate types (or sub-groups) of autistic difficulty. However, it’s also likely that these will be found to shade into one another, (which is why the term ‘spectrum’ is so useful). In practice, most children may well show a mix of features of the different sub-groups.

4. How is autism identified—and what are the criteria?

There are no medical tests which lead to a diagnosis of autism. For any child, the professionals involved need to reach a conclusion about the types of difficulty that are experienced, their severity, and the overall pattern. It is also essential to assess and take account of other difficulties that may be present. The overall picture will also need to be put in the context of the child's previous experiences and opportunities for learning. An element of professional judgement (and a degree of subjectivity) is very difficult to avoid.

Conclusions need to be based on a wide range of information from a variety of sources: a description of the child's early development and current patterns of behaviour provided by parents; observations of the child, preferably across a range of situations; reports from others involved in working with (or assessing) the child. The recognised systems of criteria (DSM-IV and ICD-10) describe the features that need to be present for a diagnosis to be made—they specify the range, the type and the severity of difficulty. However, it is important to be aware of the following points:

- There is quite a lot of room for individuals to interpret these criteria in different ways. Each system includes examples of the ways in which a particular difficulty might be revealed. However, these are only examples, rather than being complete descriptions of all the ways in which the underlying difficulties can show themselves
- When these systems are used, a particular degree of severity must be shown for a diagnosis to be made. The guidelines use phrases such as 'marked impairment', 'failure adequately to use' or 'delay in'. Interpreting these phrases still leaves quite a lot to the professional judgement and experience of the individual.
- An added complication is the fact that many (but by no means all) professionals working in this area feel that these systems are too narrow. Their view is that people with even very mild and subtle difficulties in each of the 3 core areas of impairment should be recognised as having an autistic spectrum disorder; this is often referred to as the 'broad' spectrum. Part of the increase in the levels of diagnosis that has taken place in recent years has been due to this broadening of the boundaries.
- Unfortunately, these boundaries are still quite blurred. The situation is complicated because it is generally felt that autism shades gradually into other forms of communication difficulty. Some people also think that the autism spectrum gradually merges into the 'normal' range of variation in personality and temperament. Any 'cut-off' point on what is basically a continuum must be somewhat arbitrary: two individuals on either side of the 'cut-off' are bound to have a huge amount in common.

In Leicestershire most professionals involved in this area of work think that it is important to recognise the broader spectrum. This does mean that more children are recognised as being within the 'autism spectrum'. However, it does also mean that there is more scope for differences of opinion between different professionals about exactly where the line should be drawn. Although there has been a lot of work to ensure greater awareness of the broader spectrum, and to establish higher consistency, until there are clearer and more precise guidelines some 'fuzziness' is unavoidable.

5. Why does diagnosis take so long—why did it happen so late?

On average, the age at which children are diagnosed has fallen steadily over the last 10 years. There is now much greater awareness of more typical forms of autism, and increasingly of the broader spectrum. So why, in some cases, does diagnosis take so long, or take place at such a late stage?

- The core difficulties (the triad) can be shown in many very different ways. Recognition of the broader spectrum is relatively recent and, as explained above, is still somewhat controversial. The more subtle and mild forms of difficulty may not be recognised as significant or may not be seen as sufficiently severe to warrant a diagnosis (especially if either of the 2 main diagnostic systems are used)
- Reports or observations of the child's behaviour across a range of settings, and over time, may not be available. Detailed information about the child's early development is particularly important
- It is common for autism to occur alongside other difficulties. It can be especially difficult to distinguish severe learning difficulty or language disorder from autism—especially in a young child. Other sorts of complicating factors such as epilepsy, sensory difficulties or various medical conditions and syndromes may make it hard to see problems resulting from autism. Alternatively, these other conditions may be treated as explanations for problems that are actually the result of autism.
- The way in which the child's problems are displayed may well change with age and will depend particularly on the extent of any learning difficulties. Judgements are needed about some quite subtle social and communication skills. Some of these skills and abilities only appear later on in children who are developing normally. Reaching a conclusion about how (or whether) these skills are developing may mean waiting until a comparison can be made with others who are developing these skills in the normal way.
- The skills a child has learned, and the environment he or she is in, will affect the extent to which any difficulties are displayed.

Deciding whether a child has or has not got autism is a complex task. It is extremely important to come to the right conclusion. It may be necessary to monitor the child's progress over a period of time. The way the child responds to teaching and therapy may also shed light on the nature of his or her difficulty. It is also usually necessary to get the opinion of other professionals about other aspects of the child's development. All this inevitably takes time but, for this reason, it is also vital that any avoidable delays are kept to a minimum.

6. Who makes the diagnosis?

In Leicestershire, Leicester and Rutland we have focussed on joint working with a range of professionals to ensure that children's and young people's needs are identified as early as possible and appropriate provision made available. A Pathway is now in place to help make diagnosis of children and young people who may be on the autism spectrum predictable and consistent. In practice this means that all agencies including Community Health Services, Local Authorities and Specialist

Stage 1: Initial concerns re Communication/social interaction and gathering information

- Concerns about a pre-school child's development (and specifically about the possibility of autism) may be noticed by yourselves and picked up by a health visitor or a family doctor.
- Speech and Language Therapists often become involved at a relatively early stage, they have substantial experience in recognising children who may subsequently be diagnosed.
- Preschool practitioners in an early years setting or educational practitioners in schools may also identify children who may have some additional needs. They may then refer on to an Educational Psychologist for assessment.
- If possible autism spectrum needs are suspected then the child or young person should be referred to the Children's Community Health Service (CCHS) or to Child and Adolescent Mental Health Services (CAMHS).
- At this point a professional who will take the lead for the child's assessment should be identified. This person should be someone who is working closely with the family (with your consent) and all other professionals will be informed.

Stage 2: Referral for Health Assessment

- If your child is under 7 years of age at this stage they will be referred to a paediatrician (a doctor specialising in children's health and development), to consider and exclude any additional health needs or diagnosis
- If your child is over 13 years of age they will be referred to the Child and Adolescent Mental Health Service for assessment.
- Children between 7 and 13 years can be referred to either service.
- Referral to Speech and Language Therapy will be considered at this time if the service is not already involved.

Stage 3 Comprehensive assessment

- At this stage the lead person should consult all agencies involved with the child, with your permission, as part of the assessment process
- Information will then be gathered from all the agencies involved (including yourselves), followed by a multiagency meeting to share the information
- At this point your child or young person may be diagnosed as having needs on the autism spectrum. A minimum of two agencies who are able to make a diagnosis should be involved in the identification of autism. (These include Clinical Psychologists, Educational Psychologists, Paediatricians and Psychiatrists). This stage enables professionals to resolve most uncertainties.

Stage 4 Outcome of Assessment

- At this stage, if the professionals agree, your child or young person can be identified as being on the autism spectrum or as having an autistic spectrum disorder. This should be confirmed to you in a face to face meeting with the professional who has diagnosed AS and this will also be confirmed in writing. Information about support and agencies should be given to you at this stage. For families of preschool children this will include the opportunity to attend the Early Bird programme or Early Bird Plus programme for families of slightly older children
- There will be a discussion with you about how and when to share the outcomes of the process with your child or young person, taking into account their age, developmental level and your wishes
- If you disagree with the outcome of the assessment process, the information can be passed to the 'Autism Reference Group' a group of professionals and parents who can review all the information.

Stage 5: Transition

Professionals from various agencies will continue to work with your child for as long as necessary, and will be referred to a Personal Connexions Advisor for young people aged above 13 years.

7. If my child has been diagnosed, will he or she get extra help at school?

The brief answer to this commonly asked question is 'that depends'. Leicestershire has made a big commitment to meeting the needs of children within the autism spectrum and provides a range of services for them and their families. However, it is important to emphasise that there is no automatic link between a diagnosis and any particular package of extra help. The reasons for this are as follows:

- Leicestershire accepts the importance of recognising what is usually referred to as the 'broad spectrum'. Over the years the 'boundaries' of the diagnosis have been extended to include people with much milder and more subtle forms of difficulty in terms of the triad. People who are described as having needs within the autism spectrum actually form a very, diverse group. This is the case not just in terms of the severity of their autism and the way the underlying difficulties show themselves; it also applies to the range of additional difficulties (and strengths) that these individuals have.
- Because of this diversity, it is impossible to base decisions about what help a child or family needs on the 'label' that the child has been given. The diagnosis does provide pointers, but it is just a first step in the process of assessing needs. Though diagnosis and assessment of need are related, they

are two distinct and different issues. This is recognised in the framework of legislation that the Local Authority has to operate within. Additional help is allocated according to individual need rather than by any categorisation.

- The framework of legislation also lays down guidelines for making decisions about providing extra help. The guidelines and rules are there to ensure that resources are allocated fairly that they go to children with the most severe difficulties, according to need, and according to explicit criteria. Statutory assessment (or 'statementing', as it is often called) is only carried out where a child has the most complex and severe needs and where the child may require more help or expertise than can normally be made available in his or her school.
- Any concerns about whether your child's needs can be met in his or her school should be discussed, in the first instance, directly with the school's special needs co-ordinator or Head. The Local Authority has a Parent Partnership Service whose responsibilities include supporting parents whose children have special educational needs. They are also responsible for the 'Independent Parental Supporters,' trained volunteers who support parents directly in discussions and negotiations with schools. The Leicestershire, Leicester and Rutland Parents and Carers Council may also be able to help (07968 857598)
- Leicestershire Local Authority has an Autism Outreach Service that provides support to pupils within the autism spectrum. Schools can refer direct to the service if they have a pupil with a diagnosis. Support is directed according to need and training is provided for schools. The Autism Outreach Service can be contacted on 0116 305 9400.
- The Psychology Service is also a useful point of contact telephone: 0116 305 5100
- Schools can also access an online training resource on various aspects of the autism spectrum and how to best support children and young people provided by the Department for Children Families and Schools called the Inclusion Development Programme (web link: nationalstrategies.standards.dcsf.gov.uk/primary/features/inclusion/sen/idp)
- Each year the Autism Outreach Service runs two series of workshops for the parents and carers of children within the autism spectrum. These workshops are open to all Leicestershire families who have a child identified as being on the autism spectrum and are free of charge.

If you require this information in another version e.g. large print, or an alternative language, please telephone 0116 305 9400 or email: sts@leics.gov.uk



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Further details available on the website:

www.leics.gov.uk/education

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