

Autism – What every parent needs to know

You may have read reports in the press or watched television documentaries about families who have been affected by autism. Perhaps you think that your own child shares some of the characteristics associated with autism. A number of organisations are researching the possible causes of autism in order to discover if it has a genetic origin. The research so far has highlighted that some chromosomes (e.g. 2, 3, 7, 15, X) may carry genes linked to autism but the evidence is not conclusive. But it is possible for a child to be autistic and have another disorder as well. When your child already has a chromosome disorder, an additional diagnosis of autism may seem unnecessary but it could be very helpful. People have greater awareness of autism and its associated behaviour difficulties. The more you and the professionals know and understand about **all** the reasons for your child's difficulties, the better the chance of getting the right type of help.

What is Autism?

Autism is part of a group of disorders, known as Pervasive Developmental Disorders (PDD) and affects the way the brain processes information and how a person communicates and relates to others. It describes children and adults who may show: -

- Poor social interaction:
 - 'distant' and unable to play with other children;
 - have to be prompted to share what they have seen or done;
 - stare or use facial expressions and gestures differently to other children of the same developmental age.
- Limited verbal and non-verbal communication skills:
 - does not copy or imitate, such as waving back to you, returning the ball you have thrown;
 - will not point or gesture to communicate;
 - where there is some language, unable to start or continue a conversation;
 - language can be repetitive, or odd;
- Limited interests and activities that tend to be repetitive:
 - hand or finger flapping, twisting; intense interest in activity or object that is out of the ordinary, such as car number plates or twirling pieces of string;
 - sticking to a strict and unvaried routine and unable to accept change
- Lack of imaginative activity:
 - unable to take part in 'make-believe' play with dolls, toys, or other people
- Unusually high or low sensitivity to outside world:
 - not able to filter out unnecessary noises such as outside traffic, distant conversations;
 - unable to hear or acknowledge certain levels of sound, or likes noisy, crowded places;
 - may have no sense of smell or prefer strong smelling odours, or can find some smells too intense such as perfumes, shampoo;
 - prefers strong flavours in food or finds certain textures of food unpleasant;
 - touching can be painful and it is difficult to brush or wash hair, clothes must have the right feel, in some cases children need to feel more touch through hugging, or even self-harming;
 - children can experience visual distortions, or blurred images;
 - balance may be affected and so rocking, spinning or swinging helps; no awareness of their body so stands too close, bumps into people
- Lack of empathy:
 - inability to see things from another person's point of view
 - can't imagine what they feel or think
 - difficulty in predicting what another person might do

These difficulties can affect children differently; for some it is severely disabling, others are only mildly affected and can live independent lives. Autism is best thought of as a spectrum or range of difficulties and Autistic Spectrum Disorder (ASD) is the term most frequently used.

What causes Autism /Autistic Spectrum Disorders (ASD)?

At the moment no one knows why ASD occurs. There is evidence of a genetic link but it is unlikely to be a single gene that is responsible. Maybe one or more combination of several different genes may determine whether a child develops ASD. Research has shown that children with Fragile X or Tuberous Sclerosis have a greater tendency to develop ASD. Parents sometimes worry that vaccination or difficulties during pregnancy and childbirth may have contributed but so far there is no reliable scientific research to prove this. It is such a complex disorder that there are probably a number of factors, such as diet, environment, illness or medical condition that are involved.

Assessment

Most children develop ASD during the first three years. It is possible to make a diagnosis at an earlier age but it rarely happens before the age of two. When a child already has a chromosome disorder or other difficulties it can disguise their ASD symptoms; this means that some children are not diagnosed with ASD until they are much older. There is no medical test or physical examination to show if a child has ASD. Often a parent or teacher will be the first to show concern about a child's behaviour. It is usual for a child to be assessed by a team of professionals, which may include: -

- Speech and Language Therapist
- Clinical Psychologist
- Social Worker
- Psychiatrist.

There is a lengthy interview with the parents to discuss their child's early years and development, and to talk about how their child relates to others, communicates, and behaves. A child will be observed and their behaviour studied and recorded. This may happen at school, in the home and at Child Development Centre. A child will be tested to find out how they use or understand language. The assessment will also consider medical evidence in order to rule out other explanations for the child's difficulties. This may seem quite an ordeal but it usually quite informal and involves playing games, drawing, reading and talking. The observer records the information as the other person works with the child.

Sometimes it is not always possible to reach a definite answer. Many chromosome disorders share similar patterns of behaviour linked to ASD, such as hand flapping, communication difficulties, and poor eye-to-eye contact.

If you feel unhappy about a decision, you are entitled to question it and ask for a second opinion.

Occasionally even the professionals can disagree with each other. The National Autistic Society has set up a Centre for Social and Communication Disorders in London. (Contact details below). They aim to make a detailed diagnosis and assessment and give advice on what services are required. It is not part of the National Health Service and your local Health Authority has to agree to fund the appointments. So a child would have to be referred by a professional from your local Child Development Centre or Behaviour Clinic.

Treatments and Cures – Fact or Fiction?

There is no cure for ASD. There are claims that some children have recovered from autism but long-term studies suggest that most children will continue to display features associated with the disorder throughout their lives. There are treatment programs that can help a child with ASD make progress; special educational methods, early intervention programs, therapies and behaviour strategies. As a child grows older their understanding and use of communication and more appropriate social behaviour may improve with the right support. There is no specific medication for ASD. Some drugs can help relieve anxiety, control mood swings and improve attention spans. Drugs are sometimes over-subscribed, as a way of controlling behaviour, often with long-term side effects (weight loss or gain, sleep disorder, nausea). It is important that other methods of managing behaviour and reducing anxiety are considered first, before turning to medication. If medication is necessary then it should be part of an overall planned behaviour strategy.

What can be done to help?

ASD children need help to communicate, develop language and manage behaviour. Many of the strategies used are the same for children with other disabilities.

Speech therapy will include games or circle-time that will develop a child's understanding of turn taking, the first steps to communication. If a child has little or no spoken language then the therapist will try a signing system like Makaton, or Picture Exchange System (PECS), where a child selects pictures or symbols to communicate. Simple phrases, starting with the child's name, will get their attention and are easier for them to follow. For example, "Susan, sit on the chair. Susan, drink the juice" will be easier to understand than, "Sit down and finish your drink, Susan".

Behaviour management will help to increase the range of suitable behaviours and discourage the less desirable behaviours. The local Child Development Centre or clinical psychologist will give advice, for example, about the best way to encourage your child to sit quietly at the table or start toilet training or improve concentration.

Portage is a home-visiting service for pre-school children who have additional support needs. It aims, through play activities, to develop children's development, communication and social skills. The portage worker will visit each week for a period of time and work with the child and family. The National Autistic Society (NAS) has their own program for young children called **Early Bird** and for five to eight year-olds they are developing the **Early Bird Plus** scheme.

Education, in an appropriate way, is still the most effective way to help a child with ASD or any other disability. The additional diagnosis of ASD will enable the school to develop a social skills and communication programme that is most suitable for the child. It is important to consider carefully how a mainstream school will carry out the programme, and what resources are available.

Therapies and Intervention programs are many and varied and most have not been clinically tested. What works well for one child may not be suitable for another. Parents have to decide, based on their own knowledge about their child, what would be the best approach. The NAS will have more detailed information for parents. Briefly, the main therapies are: -

Lovass An intensive, 40-hour-a-week, program that uses a team of trained helpers. The skills that are taught are broken down into small steps or stages. As each step towards the skill is achieved, the child receives praise and small rewards. When a child has learned the more basic self-help skills the program moves onto to develop verbal and non-verbal imitation skills and toy play. They will reinforce and reward desirable behaviour and ignore the undesirable behaviour.

TEACCH (Treatment and Education of **R**elated Communication **H**andicapped Children)

This method uses visual cues (pictures or symbols) to help a child understand what is planned for the day and how the work is to be done. These visual cues make it easier for the child to process and understand instructions. Controlling the environment is important. Children sit at workstations that are designed to reduce any distractions.

PECS (Picture Exchange Communication System)

A behaviour-based program that uses, according to a child's developmental level, objects, pictures or symbols. They have to exchange them for something that they like and want. It helps non-verbal children learn how to express their needs and how communication works.

Schools often use a number of different approaches according to what is best suited for a child. In all cases parents will have to be involved with the program and continue it at home, usually for a number of years. It is important to consider the likely effects on the child and the family before adopting one particular approach. A number of groups and organisations exist that will have information to help parents decide what would be best.

Many children with rare chromosome disorders share some of the characteristics of ASD behaviour. It may not mean that they have ASD. An assessment for ASD will help to identify if other teaching methods or parenting skills are needed or more suitable. If you are concerned then speak to your GP, the school, a health visitor or paediatrician.

Contact Details

The National Autistic Society: Autism Helpline **0845 070 4004** (local rate) Mon-Fri 10am –4pm
www.autism.org.uk Web site has many useful information sheets and details of local support groups. They also operate a confidential, Parent-to-Parent, help line. Freephone **0800 9520 520** and leave a message. It is a UK wide network of parent volunteers. Calls are directed to the nearest scheme and the next on-duty parent will call you back. You can also find out about the nearest **Early Bird** scheme.

The Centre for Social and Communication Disorders: Elliot House, 113 Masons Hill, Bromley, Kent, BR2 9HT. Tel: **020 8466 0098**

Contact a Family: Freephone Helpline **0808 808 3556** Mon-Fri 10am –4pm
www.cafamily.org.uk

National Portage Association: not every area in UK will have portage. Contact the association to see what is available near you. **01935 471 641** Mon-Thu 9am – 1pm
www.portage.org.uk

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