

Recognising Autistic Spectrum Disorder

A National Autistic Society Publication

National Initiative: Autism Screening and Assessment (NIASA)

This initiative, formed by the Royal Colleges of Paediatrics and Child Health, and of Psychiatrists, will produce its report by 2003. It will make recommendations for good practice at regional level across the UK in the identification, assessment, diagnosis and access to interventions for preschool and primary phase children with autism spectrum disorders. Please return the attached questionnaire to receive a free copy by email of this report. Copies will also be available via NAS Publications at a charge. Telephone: 020 7903 3595.

Summary

Autistic spectrum disorders are a group of developmental disorders. Childhood autism has received the most attention and is the best understood of the group.

Children with autistic spectrum and related disorders will require extra help educationally, often at schools that cater specifically for autism.

Behaviour problems are common and require treatment usually in the form of behaviour management. Occasionally psychiatric treatment may be indicated.

Autism is a lifelong disability and therefore continued social support is usually required, sometimes with input from mental health services.

REFERENCES

Filipek, P. A. et al. 1999. The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29, pp. 439-484. Available from the NAS Information Centre, £2.

World Health Organisation. 1992. *International Classification of Diseases*. 10th ed. Geneva: WHO.

How can The National Autistic Society help you and your patients?

FINDING THE ANSWERS

The National Autistic Society information centre can point you to references or give information on tertiary referral.

Telephone: 020 7903 3599 (Mon-Fri 10.00-14.00) or email: info@nas.org.uk

Please also see the professionals' section of The National Autistic Society website www.nas.org.uk/profess/health.html

Where can your patients get help?

THE NATIONAL AUTISTIC SOCIETY AUTISM HELPLINE

Telephone: 0870 600 85 85 (Mon-Fri 10.00-16.00) or email autismhelpline@nas.org.uk or write to:

Autism Helpline, 393 City Road, London, EC1V 1NG

The Helpline has trained staff able to discuss particular problems with callers and can provide information on diagnosis, support, and local support groups.

The National Autistic Society (NAS) is the UK's leading autism charity. Founded in 1962, it:

- Runs specialist day and residential schools and adult services
- Provides training to parents, carers and professionals
- Supports local authorities in the development of their own specialist services
- Operates a helpline for people affected by autistic spectrum disorders and their families
- Offers specialist diagnosis and assessment services
- Encourages research into the cause of autism
- Supports local groups and families around the country
- Co-ordinates the work of volunteers on nationwide Parent-to-Parent and Befriending schemes
- Provides a volunteer run Advocacy service to help parents understand the special educational entitlements for their child
- Works to increase public and professional awareness of autism and Asperger syndrome
- Runs an international conference on autism

www.nas.org.uk

Autism Helpline: 0870 600 85 85 (10am-4pm, Mon-Fri) autismhelpline@nas.org.uk

Information Centre: 020 7903 3599 (10am-2pm, Mon-Fri) info@nas.org.uk

'Autistic spectrum disorder' is the term frequently used to refer to the group of disorders included under the general heading of the pervasive developmental disorders (PDD) in the International Classification of Diseases (World Health Organisation, 1992)¹. This group of disorders are 'characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities.'

This classificatory system has been designed to accommodate the needs of clinicians, researchers and administrators, but the terminology can be confusing for parents, teachers and others.

Nevertheless, the classification does effectively demonstrate that there are a range of disorders which share essential features, and that simply identifying those with classical autism does not address the extent of the problem. The family of autistic spectrum disorders includes Asperger syndrome (currently distinguished from autism by absence of significant language delay, and general intellectual skills in the normal range), pervasive developmental disorder not otherwise specified (PDD-NOS), and childhood disintegrative disorder. The National Autistic Society estimates a prevalence rate of people with autistic spectrum disorders of 1 in 110 people. For an average list size of 2,000 people, each GP is likely to have up to 18 people on the autistic spectrum on their list.

Aetiology

The precise cause is not known, but research indicates that genetic factors are important. In some cases autistic spectrum disorders may also be associated with various conditions affecting brain development, such as maternal rubella, tuberous sclerosis or post-encephalitic states but the frequency of such findings remains uncertain.

Recognising the clinical features

Individuals who are considered to be on the autistic spectrum are in many ways very different from each other. The range of intellectual ability extends from the severely learning disabled range right up to normal or even superior levels of intellect. Similarly, linguistic skills range from those who are mute to those who display complex, grammatically correct speech.

All such individuals have difficulties in three main areas. Different authors have used slightly different terminology to describe this cluster of symptoms, but the concept of the 'triad of impairments' is widely used.

Triad of impairments

IMPAIRMENT OF SOCIAL INTERACTION

This refers to an impaired ability to engage in reciprocal social interactions. The most severely affected individuals seem aloof and uninterested in people. Others desire contact, but fail to understand the reciprocal nature of normal social interaction. In consequence their attempts at social interaction are clumsy, awkward and one-sided. Some passively accept the attentions of others but do not reciprocate.

IMPAIRMENT OF SOCIAL COMMUNICATION

The whole range of communicative skills may be affected. A significant proportion of individuals with classical autism fail to develop useful speech. Even when the mechanics of language are mastered, the person with autism has difficulty using it for the purpose of communicating with others. Intonation is inclined to be abnormal and the non-verbal aspects of communication such as eye-to-eye gaze, use of gesture and facial expression can be impaired.

[1] World Health Organisation (1992) *International Classification of Diseases*. 10th ed. Geneva: WHO

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ref: NAS/GP/102002

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Displays indifference

IMPAIRMENT OF IMAGINATION

People with autism have great difficulty thinking imaginatively. This is demonstrated by pretend play, which will be absent or repetitive in children with autistic spectrum disorders. Whether this is directly related to the development of rigid and repetitive behaviours has not been established.

Other characteristics

REPETITIVE AND STEREOTYPED BEHAVIOURS

People may be familiar with the image of children with autism obsessively lining up toys, repeatedly spinning objects or flapping their hands in the periphery of their vision. As development proceeds, however, the focus of attention tends to shift from physical activities to the collection of information. This is particularly true of more able children who may accumulate facts about specific topics.

Characteristically, the themes of such preoccupations are unusual and the focus extremely restricted. Additionally, they do not become the currency of social exchange in the way that collecting football stickers or knowledge about computer games often does for typically developing children.

JOINT ATTENTION BEHAVIOURS

Joint attention behaviours are attempts to monitor or direct the attention of another person. They include gaze monitoring, pointing and showing. These behaviours are normally present by age 9-14 months but are rare or absent in children with autism.

Screening

At present there is no suitable test for the universal screening of preschool children for autistic spectrum disorders. Nevertheless identification of autistic spectrum disorders can be improved by recognising those signals which might indicate further assessment is needed. These red flags include concerns around communication (eg. not responding to name, not pointing or waving goodbye, delayed language), social interaction (eg. seems to prefer playing alone, is very independent, does not smile socially) and behaviour (eg. has unusual attachments to toys, is oversensitive to certain textures or sounds, is hyperactive, unco-operative or oppositional).

THE RED FLAGS FOR AUTISM

Absolute indications for immediate further evaluation:

- No babbling by 12 months
- No gesturing (pointing, waving, bye-bye, etc) by 12 months
- No single words by 16 months
- No 2-word spontaneous (not just echolalic) phrases by 24 months
- ANY loss of ANY language or social skills at ANY age

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As autistic spectrum disorders are developmental their presentation will vary with age and, in any one individual, vary over time. The characteristics of autistic spectrum disorders may be more prominent at some ages than others. Thus a clearer understanding of normal social, behavioural and language development is required among parents, carers and professionals. Existing child developmental surveillance programmes undertaken by primary care teams, including health visitors, offer a context within which better detection can occur. It is important to remember that autistic spectrum disorders may occur in those with medical conditions such as early epilepsy and that learning and psychiatric co-morbidities are common.

Some problems

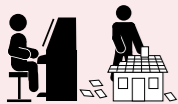
DIAGNOSIS

Parents of children with autism often report dissatisfaction with the diagnostic process. On average parents first become concerned when their child is around 18 months of age and first seek help when he or she is about two years. However, it often takes years before a diagnosis is made.

Not infrequently parents are reassured about their initial concerns only to discover later that their child has autism.



Bizarre behaviour



But some can do some things very well, very quickly but not tasks involving social understanding



Inappropriate laughing or giggling



Echolalic – copies words like parrot



Handles and spins objects



Indicates needs by using an adult's hand

BEHAVIOUR PROBLEMS

A tendency to engage in stereotyped, repetitive behaviours is a central feature of autistic spectrum disorders. In addition, other maladaptive behaviours often develop such as temper tantrums, phobias, sleep problems, aggression or self injurious behaviours.

Behaviour management techniques have proved a valuable way of addressing these problems. It is important to remember, however, that people with autistic spectrum disorders will not respond in the conventional way to standard behaviour modification techniques. They will not, for example, understand the rewards of social reinforcement. However, behavioural treatment, usually carried out by a clinical psychologist can be a useful intervention. Sometimes community psychiatric nurses or other mental health professionals may also have developed expertise in this area.

Psychotropic drugs may be indicated for the treatment of a specific mental disorder. Whilst it is preferable to avoid drugs in the treatment of longstanding maladaptive behaviours they are sometimes necessary and can prove beneficial.

ADOLESCENCE AND TRANSITION TO ADULT LIFE

Not surprisingly, adolescence can be an especially testing time for people with autism and for their families. In addition to the developmental changes associated with puberty, some people with autism begin to develop a painful awareness of their difficulties, which can result in depression or behavioural problems. About one third of people with autism develop epilepsy with an onset of seizures in adolescence occurring in a significant proportion. Many adolescents, however, will only ever have one or two seizures and medication should not, therefore, be prescribed immediately.

Autism results in lifelong disability for those affected individuals. Follow-up studies have shown that the majority continue to suffer problems as adults and few manage to live independently.

For most, therefore, there will be a continuing need for social support and some will also require input from mental health professionals. Unfortunately, professionals working within adult services have often been unfamiliar with the problems of autism. It is hoped that this is changing as awareness of the disorder increases.

MRC REVIEW

The most recent review of research into the causes and epidemiology of autism was published by the Medical Research Council in December 2001. It outlines current understanding and proposes a framework for future research into this most complex condition. The document is available from the MRC, 20 Park Crescent, London W1B 1AL or on its website (www.mrc.ac.uk)

Consultations with people with autism

Whilst it is important to emphasise that people with autism are individuals with their own characteristic ways of relating to others, there are certain areas which are worth considering when consulting with them. First, people with autism find changes in routine difficult to handle. They may be stressed by having to break their routine to visit their GP or Health Visitor. Some are hypersensitive to noise and others fearful of crowds. They often have difficulty waiting their turn.

Clearly, therefore, a waiting room can be an extremely stressful environment for someone with autism. They may be completely unable to tolerate such an experience or else become so anxious that the consultation is adversely affected.

Some autistic people have an altered sensitivity to pain. They may be oblivious to injury, or alternatively, experience the texture of certain fabrics as painful. The possible implications for medical consultations are obvious.

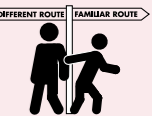
They are likely to have difficulty understanding what is said to them. Even those with seemingly good expressive speech are likely to struggle with non-literal communications such as figures of speech, sarcasm or jokes. They often take what is said to them literally and if given an appointment for 2 o'clock will expect to be seen at precisely that time. Similarly, if told they are to be prescribed 'medicine' they might not accept medication in tablet form from the pharmacist.

Often they find information presented visually easier to understand.

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www.nas.org.uk Tel: 020 7833 2299



One-sided interaction



Variety is not the spice of life



Does not play with other children



No eye contact



Talks incessantly about only one topic



Lack of creative pretend play



Joins in only if adult insists or assists