Understanding

Autism in children and adolescents



Edward

Three-year old Edward sits in a corner of his family sitting room facing the wall, clutching a Thomas the Tank Engine toy. He rocks gently and hums to himself. His little two-year old sister, Emily, is happily playing, busily filling her mother's lap with soft toys. Emily trots across to her brother and speaks to him. He turns his head away. She gives him a push and Edward collapses to the floor. Emily tries to pull him up, but Edward makes no response at all. Finally, in a desperate attempt to gain his attention, she grabs the toy from his hand. He makes no protest, but behaves as if he has not even noticed.

Mary

Mrs Johnson, the head of the nursery, was called in to observe Mary. Mary had only just joined the nursery but already her unusual behaviour was impossible to ignore. Whilst the other children seemed busily engaged, chattering and playing, Mary just trotted round and round the large room, flapping her hands and staring fixedly ahead while apparently mumbling to herself. When her teacher tried to encourage her to join the painting table she moaned, pulled herself from the teacher's grasp and carried on her circuit. At no time during the course of the morning did she seem to respond to anyone.

Peter

Peter sat with his mum and dad in the doctor's waiting room, systematically moving piles of magazines from the shelves to the table. When their time came to see the doctor, Peter vigorously resisted any attempt to take him out of the waiting room and began moving more and more magazines. When Peter's dad said very firmly that they would have to go upstairs, Peter flung himself on the floor, lying on his back, kicking. It took both parents to get him out of the room, still kicking and screaming. Their GP thought that Peter might be autistic, and referred him to a specialist.



hat is autism?

Each of the above vignettes describes a child with autism. Autism is a developmental disorder that severely affects young children in their emotional, social and mental development. On meeting someone with autism we are confronted with a strong sense of a person lost in a world of their own whom we are unable to reach emotionally.

Autistic children may ignore us despite all attempts to gain their attention. Some parents feel that if they were to disappear tomorrow their child would not notice. Other children often make their parents and siblings feel like servants whose sole task is to maintain an order dictated by themselves. It's only too easy to feel as if one is no more important than a 'piece of furniture'. A parent may not be asked for help: rather, the child may take the parent's hand and place it on a doorknob. The child does not request assistance but literally 'wants a hand'. He or she needs the function that the hand performs, and the person who is attached to the hand is incidental. This can make any parent feel distanced from their child.

They seem to lack a sense of a world in which there are people who could be interesting and interested in them, and often seem to relate better to things than to people. They can be quite content to be alone and may even treat the friendly approach of others as an intrusion. They can get locked into their own familiar activities, which they may repeat endlessly without any sense of boredom. They often accompany these activities with strange body movements, such as rocking back and forth, or flapping their hands.

They do not seek communication with people in the ordinary way. For those who develop language, speech is always strange and often repetitive – they cannot hold a conversation. They do not play imaginatively and frequently carry out strange repetitive rituals. There is often severe developmental delay in all areas of the child's functioning.



ow is a diagnosis made?

Autism was first described by Leo Kanner in America in 1943. He observed 11 children who shared the features outlined above. His observations and the detailed accounts provided by the parents led him to conclude that these traits grouped together to form a particular syndrome.

In the case of any disorder, the clinician must establish the existence of the necessary symptoms for a diagnosis. Three primary characteristics must be present for the identification of autism, one of which should be noticed before the child is three years old.

Impaired reciprocal social interaction

One very noticeable feature of autism is the severe difficulty in relating to others. Social difficulties include: a distinct lack of awareness of the feelings of others; a preference for being alone; an inability to understand social rules and conventions; a failure to seek comfort from others at times of distress; an impaired ability to imitate the actions of others and a lack of social and creative play.

Impaired communication

This is another primary feature of autism. Around half of the children diagnosed as autistic do not develop meaningful communicative language, and most have problems with non-verbal communication such as gestures. Those who can talk lack the usual rhythm and intonation of speech and their use of language is often odd. For example, the repetition of a familiar phrase, parroting (called 'echolalia' by professionals), mixing up the words 'you' and 'l', strange use of words and phrases, and difficulty in engaging in social conversations.

Restricted activities and interests

The third primary characteristic of autistic individuals is their limited range of activities and interests. They may engage in repetitive bodily movements such as body rocking and hand flapping and their play activity is often severely restricted and repetitive. Those with milder autism may become absorbed in very narrow topics, such as bus timetables.

Other common features

Certain other features are commonly associated with autism, although they are not necessary for its diagnosis. The reactions of autistic children to sensory stimuli may appear odd; they may become either over-stimulated, for example by certain noises,

or under-responsive, as may be seen in their lack of reaction to things that are clearly painful. They tend to have little sense of personal danger, and some inflict harm on themselves. Many autistic people appear fascinated by specific sounds or tastes. Eating and sleeping are often problematic, they may be easily distracted from what they are doing, unable to organize their activities, and have problems with abstract ideas.



re there degrees of autism?

Can you have a mild dose of autism, just as you can have a mild dose of measles? It's not surprising if parents are confused since this is an ongoing debate among specialists. Parents may be told that their child is on the 'autistic spectrum', is mildly autistic or severely autistic, has 'autistic features', has a pervasive developmental disorder or has Asperger's syndrome. Most professionals currently take the view that it is most helpful to think of autism as a continuum ranging from 'mild' to 'severe'. The characteristics described above may appear in varying magnitudes in different children. For example, while two children may actively avoid being with others, one may be gently cajoled to join in, while the other may protest vigorously with tantrums. Children with Asperger's syndrome are currently understood to lie at the less affected end of the autistic continuum: in general their language and mental abilities are less impaired, although they tend to be clumsier than other autistic individuals.



hy is it sometimes difficult to diagnose autism?

Diagnosing autism can be difficult because it resembles other disabilities of behaviour, communication and learning. Many professionals only come across a few people with the condition. This means that they are unable to identify consistently subtle distinctions between autism and similar disabilities. For several decades, the association between autism and severe learning disability has been a source of great confusion: around 70 per cent of autistic people have learning difficulties.

Language and hearing impairment can also be confused with autism. Autistic children are often initially thought to be deaf by parents and professionals. Testing usually shows this is not the case; non-responsiveness does not necessarily mean that a child cannot hear. Language impairment in children with autism includes delayed

development of speech and problems understanding language, echolalia, pronoun reversal and problems with sequencing.

Another scheme of classification – 'pervasive developmental disorder not otherwise specified' (PDDNOS) – has recently been introduced into the American diagnostic system. This is designed to recognize those children who have some of the characteristics of autism but not the full syndrome. Unfortunately, a lack of precision makes unclear the exact characteristics of these children, and has added more confusion.



hat causes autism?

There has been considerable controversy about the cause of this mysterious condition. In the past, some professionals took extreme points of view leading them to split into opposing camps. Many have asserted the evidence for an organic cause, such as a genetic one, which has led inevitably to a pessimistic view of the possibility of improvement in the condition. Others have seen autism entirely as an emotional defence against unbearable experiences – this view has often neglected the genuine developmental disorder. Nowadays, many professionals believe there can be several causes. They generally acknowledge the fact that there is a genetic predisposition to the disorder – just as in many families there can be a susceptibility to chest infections. However, this is probably not the whole story. It may be that the vulnerability is triggered by some environmental event that occurs around the time of birth such as labour complications.

Whatever the causes of autism might be, it needs to be recognized that parents themselves often feel guilty as if they are responsible for their child's condition. Parents' concerns should always be taken extremely seriously. They should be helped to understand that they have not caused the child's autism.



ow early can autism be detected?

In general, it is not possible to make a formal diagnosis of autism until a child is at least three years old. There are two reasons for this. Firstly, the three necessary characteristics for conclusive identification may not fully emerge before that age. An infant may appear to be 'emotionally hard to reach' and it may not be possible to

establish whether there are also difficulties in his or her use of language or play. Secondly, some early signs of difficulties that appear 'autistic-like' may gradually disappear as the child develops. It is important to look into whether there is anyone else in the family who may have been late in developing certain skills or abilities in the affected area.

The importance of parents' own observations and feelings about their child's development cannot be underestimated. Some parents have a sense of something awry long before the three-year watershed. They receive the full impact of the difficulties in relating to their child. Often they attribute these difficulties to themselves, and work harder at trying to reach their child. As many children with autism do not respond to their parents' voices they are initially thought to be deaf. Many parents witness their small children becoming lost in certain sensations, which serves to preclude them from their child's world. More striking is their lack of sharing – whether pointing to things of interest, or bringing something to show mum or dad. Some infants do not babble (a form of pre-speech).

Many parents often describe as 'good babies' those who are subsequently diagnosed as 'autistic'. With hindsight it becomes apparent that these were very passive babies, who did not make their needs known, rarely protested and seemed unusually content with their own company. It was only when the toddlers joined playgroups or nurseries, and failed to act like their peers, that the parents became concerned.

Although professionals are often reluctant to make a formal diagnosis before the age of three or so, more are becoming alerted to the possibility of detecting early signs of autism. This is an area that is currently undergoing research with the aim of providing checklists to aid prompt identification.



ow common is autism?

A conservative estimate puts the number of children with autism between 4 and 10 in every 10,000. The incidence of autism seems to be fairly even throughout our society: it does not appear more frequently in one particular social class or ethnic group. Further, as far as can be established, the incidence of autism is no more marked in any one nation than another. Autism is found to occur more frequently in males than in females; the ratio is approximately three to one.

The reported incidence of autism, however, does appear to be rising. This may at least be partly due to the fact that more people know about its existence – for example, through the work of the National Autistic Society, newspaper articles, documentaries and films. The motion picture *Rainman* portrayed a highly able person with autism, and drew particular attention to his difficulties in relating to others and his intolerance of change. Ten years ago few people had heard of autism; nowadays, most people have. Health visitors are now trained to be more alert to the early signs.



hat's it like for the families?

Families with an autistic child must live with a person who inhabits a mysterious world of their own. Parents can feel despairing, for they feel that they are not interesting to their children, and have no impact on them or on their behaviour.

Having a child with autism puts enormous pressures on all family members because such youngsters take an increasing amount of the family resources but cannot give very much back. Autistic children often do not sleep very well and this puts great stress on their parents. Many of these children refuse to sit at the table and eat with the rest of the family but simply graze, either helping themselves from the fridge or taking food from other family members' plates. This, too, can make it much harder to have visitors to the household, particularly for siblings: all children want to be like their friends and can be embarrassed by their brothers' or sisters' strange behaviour and simply stop inviting others home. Siblings may become under-demanding as they recognize that their parents are already over-taxed: they risk becoming assistant parents. Other children, seeing that their sibling with autism gets so much attention may, unsurprisingly, feel that this might be the way in which they too can get the notice they need. Sometimes their conduct then mirrors the worrying behaviour of their autistic brother or sister.

Because the autistic child is inflexible and unreasonable all families to some degree end up fitting in with their offspring. It is only too easy for them to become cut off from normal society when the features of everyday life can so easily be a source of persecution rather than of pleasure. A visit to the shops or the park can become a nightmare because of a child's tantrums, antisocial behaviour or strange use of language. Many parents describe developing a thick skin in order to face the rigours

of these simple excursions. Without regular ordinary daily contact with the world of children and families it becomes only too easy to lose any sense of what is normal. Because the child with autism is so inflexible, gradually but inexorably parents and siblings can get sucked into his or her world. This is the reversal of the usual situation, where parents introduce the child to the wider community.



hat do I do if I'm worried that my child may have autism?

If you are worried that your child is autistic then it is important to seek professional help immediately. Who you approach depends on your child's age. If you suspect that your baby turns away from ordinary friendly social contact then the first person to see is your health visitor or GP. If your child is already in school then your child's nursery or class teacher will be your first point of contact.

If you feel your concerns are not being listened to it is important to hold on to the fact that most parents really do know their child better than any professional. It is necessary to understand that autism is still a rare condition and most professionals will not have encountered many children with it. For this reason you should not take the situation too personally. Parents' self-help groups can be an enormous support, providing a wealth of information about responsive professionals. The National Autistic Society is a source of helpful literature and provides contact numbers for support groups.

The diagnosis of autism is sometimes a relief – especially if the parent has been worried about the situation for some time. Sometimes, however, a diagnosis is made but little follow-up advice is given. This can be devastating. If this happens to you, then do seek further help – for example, refer to someone with knowledge of the most suitable course of action.

Education

It is important to begin the 'statementing' process as early as possible. A statement of special educational needs is compiled by the Local Education Authority in cooperation with involved professionals and parents. Statementing should ensure that these needs are identified and met in order to provide consistent educational interventions at an early age from teachers with specialist training. Research shows that early educational intervention promotes the longer-term development of communication and social skills. All autistic children are unique individuals and need careful assessment to determine the most suitable educational setting. It is also essential that there is some input from trained educationalists. This is often a long

and exceptionally arduous process that many parents find demoralizing. Do seek support from professionals and parent groups.

Treatment

Claims are made for many forms of treatment and it is important that these should be carefully evaluated by such means as talking to other parents and professionals. Each year sees some new intervention that might make an extravagant claim for success. It is difficult for a concerned parent to resist embarking on anything that might possibly help their child: this means some children endure many such 'treatments'. This usually results only in confusion for the child and exhaustion for the parents. It is helpful to take a cautious approach when starting out on something new.

Clinical interventions

Clinical interventions indicate that the younger the child is when beginning treatment the greater the chances of success, as behaviours are less entrenched. As the years go by children can become addicted to their rituals. False reassurances from health professionals or other family members that your child will 'grow out of it' or that they are 'just a late developer', although well intentioned, can be harmful. Trust your own intuition. You will know if something is wrong.



seful organizations

The National Autistic Society

(NAS) 393 City Road, London EC1V 1NG, tel. 0171 833 2299. Provides a number of useful publications. Please send a sae.

Office for Advice, Assistance, Support and Information on Special Needs (OAASIS) Brock House, Grigg Lane, Brockenhurst, Hampshire SO42 7RE, tel. 0891 633201.



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| | a complete catalogue of publications available from Mind, send an SAE to |
| | Autism. Preparing for Adulthood P. Howlin (Routledge 1997) £14.99 |
| _ _ _ | Autism and Asperger Syndrome U. Frith (ed) (Cambridge University Press 1991) £17.95 Autism: An Introduction to Psychological Theory F. Happé (University College London Press 1994) £13.95 |

Mind is the leading mental health charity in England and Wales. It works for a better life for people diagnosed, labelled or treated as mentally ill. It does this through campaigning, community development, training, publishing and a comprehensive information service. Throughout its work Mind draws on the expertise of people with direct experience as users and providers of mental health services.

For details of your nearest local Mind association and details of local services contact Mind's helpline, Mind*info*Line, 0181 522 1728 from within London or 0345 660 163 outside London. Mon-Fri 9.15a.m.-4.45p.m. If you need interpretation Mind*info*Line has access to 100 languages via Language Line.

Typetalk is available for people with hearing or speech problems who have access to a minicom. To make a call via Typetalk dial freephone 0800 959598.

Mind also has six regional offices and a national office in Wales: North West Mind 21 Ribblesdale Place, Preston PR1 3NA Northern Mind 158 Durham Road, Gateshead, Tyne & Wear NE8 4EL

South West Mind 9th Floor, Tower House, Fairfax Street, Bristol BS1 3BN Trent & Yorkshire Mind 44 Howard Street, Sheffield S1 2LX

Mind Cymru 3rd Floor, Quebec House, Castlebridge, Cowbridge Road East, Cardiff CF1 9AB

West Midlands Mind 20/21 Cleveland Street, Wolverhampton WV1 3HT South East Mind First Floor, Kemp House 152-160 City Road, London EC1V 2NP

Northern Ireland Association for Mental Health Central Office, Beacon House, 80 University Street, Belfast BT7 1HE, helpline 01232 237937

Scottish Association for Mental Health Cumbrae House, 15 Carlton Court, Glasgow G5 9JP, tel. 0141 568 7000



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ISBN 1 874690 81 2 Published by Mind © Mind 1999
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