

Clinical review

Diagnosis of autism

Gillian Baird, Hilary Cass, Vicky Slonims

Parents want autism to be diagnosed as early as possible, and early intervention may improve long term outcomes. The authors of this review discuss the identification and assessment process for children with autism and autistic spectrum disorder

Newcomen Centre,
Guy's and St
Thomas' NHS
Trust, London
SE1 9RT

Gillian Baird
consultant
developmental
paediatrician

Vicky Slonims
principal specialist
speech and language
therapist

Great Ormond
Street Children's
Hospital, London

Hilary Cass
consultant in
paediatric disability

Correspondence to:
G Baird
gillian.baird@
gstt.sthames.nhs.uk

BMJ 2003;327:488-93

Autistic spectrum disorders have been the subject of increasing attention over the past few years—from the media, from clinicians, and from the general public. Stories of savants who excel in such skills as calendar calculations and detailed drawings have long been a fascination to public and clinician alike, exemplified in Dustin Hoffman's portrayal of a young man with autism in the film *Rainman*. Most recently, public anxiety about autism has been raised as a result of reports linking the measles, mumps, and rubella (MMR) vaccine with autism and inflammatory bowel disorder and a rise in the prevalence of autism.^{1,2} This has resulted in a serious fall in immunisation rates,³ despite the epidemiological evidence of a lack of association,⁴ and strong reassurance from the Department of Health and the Royal College of Paediatrics and Child Health about the safety of the MMR vaccine. Parents of children with autism continue to express the view that the medical profession does not take their concerns about possible causes of autism seriously. "Miracle cures" for autism—for example, with secretin—have received wide publicity through television and raised enormous hopes before being placed in their proper context by double blind trials that have not confirmed a curative effect. We consulted recent reviews, specialist journals, and recent Medline papers on the diagnosis of autism.

What is autism?

Autism is a behaviourally defined disorder, characterised by qualitative impairments in social communication, social interaction, and social imagination, with a restricted range of interests and often stereotyped repetitive behaviours and mannerisms. Sensory hypo-sensitivities or hypersensitivities to the environment are common features. Criteria for the diagnosis of autism are set out in the ICD-10 (international classification of diseases, 10th revision) and the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition (DSM-IV). Two important points are essential to an understanding of this classification framework.

Firstly, although autism is behaviourally defined, it is now well recognised to be the endpoint of several organic aetiologies. These include prenatal insults such as rubella infection, untreated metabolic disorders such as phenylketonuria, anticonvulsants taken in pregnancy, localised lesions as in tuberous sclerosis, and postnatal

Summary points

Autism is a behaviourally defined disorder, which is the endpoint of several organic aetiologies

The number of children diagnosed as having autistic spectrum disorders is increasing for various reasons

A diagnosis of autism can be reliably made at between 2 and 3 years of age

Autism does not meet criteria for screening, but surveillance throughout the preschool years is recommended

Diagnosis is by history taking, focusing on the developmental story and systematically inquiring for core behaviours, and by observation in several settings

infections such as encephalitis. However, a specific medical cause is found in only a minority of people with autism (6-10% depending on the study), albeit more often in those with pronounced learning problems.⁵ Epilepsy occurs more commonly than usual in autism and was one of the early indications that this was a neurobiological disorder and not one caused by parental behaviour. In most people with autism, genetic factors play a key role.⁶ Twin studies have shown that in monozygotic twins the chance of concordance for autism is 60%, with a greater concordance for some social impairment, compared with a much lower rate in dizygotic twins. The rate of autistic spectrum disorders in singleton siblings is 2-6%, a marked increase above population rates.⁷ Multiple genes are likely to be involved, and linkage studies have identified possible candidate genes on chromosomes 2q, 7q, 16p, and 19p. No specific candidate genes have yet emerged. Autism has been associated with many cytogenetic abnormalities, especially on chromosome 15, and is also found in fragile X syndrome.⁸ Although autism is now agreed to be a neurobiological disorder, results from structural brain scans have not shown consistency of diagnostic markers. However, functional imaging has shown



Extra references
and a care pathway
appear on bmj.com

The autistic continuum (features most often used in diagnosis*). Reproduced with permission from Wing¹⁰

Item	Manifestations†			
	Tend to be seen in the most severely disabled			Tend to be seen in the least severely disabled
Social interaction	(1) Aloof and indifferent	(2) Approaches for physical needs only	(3) Passively accepts approaches	(4) Makes bizarre one-sided approaches
Social communication (verbal and non-verbal)	(1) No communication	(2) Needs only	(3) Replies if approached	(4) Spontaneous, but repetitive, one-sided, odd
Social imagination	(1) No imagination	(2) Copies others mechanically	(3) Uses dolls, toys correctly but limited, uncreative, repetitive	(4) Acts out one theme (eg, Batman) repetitively; may use other children as "mechanical aids"
Repetitive pattern of self chosen activities	(1) Simple, bodily directed (eg, face tapping, self injury)	(2) Simple, object directed (eg, taps, spins, switches lights)	(3) Complex routines, manipulation of objects, or movements (eg, bedtime ritual, lining up objects, attachment to objects, whole body movements)	(4) Verbal, abstract (eg, timetables, movements of planets, repetitive questioning)
Language—formal system	(1) No language	(2) Limited—mostly echolalic	(3) Incorrect use of pronouns, prepositions; idiosyncratic use of words or phrases; odd constructions	(4) Grammatical but long winded, repetitive, literal interpretations
Responses to sensory stimuli (oversensitive to sound, fascinated by lights, touches, tastes, self spinning; smells objects or people; indifferent to pain, heat, cold, etc)	(1) Very marked	(2) Marked	(3) Occasional	(4) Minimal or absent
Movements (flaps, jumps, rocks, tiptoe walking, odd hand postures, etc)	(1) Very marked	(2) Marked	(3) Occasional	(4) Minimal or absent
Special skills (manipulation of mechanical objects; music; drawing; mathematics; rote memory; constructional skills, etc)	(1) No special skills	(2) One skill better than others, but all below chronological age	(3) One skill around chronological age—rest well below	(4) One skill at high level well above chronological age, very different from other abilities

*Other clinical features are seen in disorders in the autistic continuum, but they are not listed here because they are not mentioned in the various sets of criteria considered essential for diagnosis.

†The manifestations of each item (numbered 1 to 4 under each heading) are arbitrarily chosen points along a continuum. In reality, each shades into the next without any clear divisions.

abnormalities of face processing (the area of the fusiform nucleus) in several studies.

Secondly, despite the organic basis of the disorder, the diagnostic criteria have been derived through consensus, rather than being organically based; no biological "test" exists for autism. Diagnostic cut-offs have been hard to define, because the manifestation of the core impairments and behaviours of autism varies greatly from person to person, as shown in the table.^{9 10} Symptoms vary in any single person with autism, and as autism is a developmental disorder change occurs over time.¹⁰

The diagnostic manuals have undergone several revisions altering the criteria for autism and its subcategories, which are defined according to the age and type of onset, the associated features, and the severity of the core features (for example, autism or autistic disorder, Asperger's syndrome). Attempting to categorise what is essentially a dimensional disorder is inevitably problematic; the reliability of subgroups varies across studies, and their long term relevance is uncertain.¹¹ Many clinicians find that although the term "autistic spectrum disorder" does not appear in either the DSM-IV or the ICD-10, it is much more easily understood by parents and professionals than "pervasive developmental disorders," which is the terminology of the diagnostic manuals. The two terms are now used almost synonymously. The word "spectrum" implies several dimensions that need to be described to give a complete picture of an individual.

Is autism increasing in prevalence?

The number of children diagnosed as having autistic spectrum disorders is increasing.¹² Studies investigating this phenomenon have concluded that several factors account for the increase—for example, changing

conceptualisation to a spectrum rather than a core categorical condition; changes in diagnostic methods; and the inclusion of children with disorders such as attention deficit hyperactivity disorder, Tourette's syndrome, or tuberous sclerosis as also having autistic spectrum disorder. The prevalence of the broad spectrum of disorders of autism (determined with current diagnostic tools) is agreed to be approximately five to six per 1000 in younger children. The United Kingdom working party (National Initiative for Autism: Screening and Assessment (NIASA)—published as the *National Autism Plan for Children*¹³), which reviewed the evidence, used this estimate as the basis for planning services for diagnosis and intervention for young children with autism. Most studies of prevalence have been carried out in young children (4-5 years of age). As some features of autism may be more obvious in the younger child, prevalence ascertained on current behaviour in adolescence or adult life may be different.

Identification of autism

Until recently, diagnosis of autism was often delayed until mid-childhood, especially if language delay was not present.¹⁴ Retrospective reports suggest that most parents identify the onset of first concerns at about 18

Box 1: Features that may discriminate children with autism early in childhood

- Lack of social smile, lack of appropriate facial expression, poor attention, impaired social interaction
- Ignoring people, preference for aloneness, lack of eye contact, lack of appropriate gestures, lack of emotional expression, less looking at others, less pointing, less showing objects in the second year

Box 2: Alerting signals of possible autistic spectrum disorder¹³

- In the first year of life there are usually no clear discriminating features, but parental concerns should be elicited
- Between 2 and 3 years of age, concerns in the following areas should prompt referral¹¹

1. Communication

Impairment in language development, especially comprehension; unusual use of language; poor response to name; deficient non-verbal communication—for example, lack of pointing and difficulty following a point and failure to smile socially to share enjoyment and respond to the smiling of others

Absolute indicators for referral

- No babble, pointing, or other gesture by 12 months
- No single words by 18 months
- No two word spontaneous (non-echoed) phrases by 24 months
- Any loss of any language or social skills at any age¹²

2. Social impairments

Limitation in, or lack of imitation of, actions (for example, clapping); lack of showing with toys or other objects; lack of interest in other children or odd approaches to other children. Minimal recognition or responsiveness to other people's happiness or distress; limited variety of imaginative play or pretence, especially social imagination (that is, not joining with others in shared imaginary games), "in his or her own world;" failure to initiate simple play with others or participate in early social games; preference for solitary play activities; odd relationships with adults (too friendly or ignores)

3. Impairment of interests, activities, and other behaviours

Over-sensitivity to sound or touch; motor mannerisms; biting, hitting, or aggression to peers; oppositional to adults; over-liking for sameness or inability to cope with change, especially in unstructured setting; repetitive play with toys (for example, lining up objects); turning light switches on and off, regardless of scolding

months of age. However, early videos taken by parents at around the first birthday may show the features in box 1, which discriminate the child later diagnosed as having autism from other children of the same age.¹⁵

Box 3: Features that may discriminate children with autism in later childhood¹³

In school age children, the following features should alert teachers and others to the possibility of autistic spectrum disorder and trigger discussion with parents and possible implementation of the local referral pathway

1. Communication impairments

- Abnormalities in language development, including muteness and odd or inappropriate prosody
- Persistent echolalia
- Reference to self as "you," "she," or "he" beyond 3 years
- Unusual vocabulary for child's age or social group
- Limited use of language for communication or tendency to talk freely only about specific topics

2. Social impairments

- Inability to join in with the play of other children or inappropriate attempts at joint play (may manifest as aggressive or disruptive behaviour)
- Lack of awareness of classroom "norms" (criticising teachers; overt unwillingness to cooperate in classroom activities; inability to appreciate or follow current trends—for example, with regard to other children's dress, style of speech, or interests)
- Easily overwhelmed by social and other stimulation
- Failure to relate normally to adults (too intense or no relationship)
- Showing extreme reactions to invasion of personal space and extreme resistance to being "hurried"

Studies have shown that a diagnosis of autism can be reliably made at between 2 and 3 years of age, although a diagnosis of the broader autistic spectrum is less reliable at this age than in older children.^{16 17} Parents want a diagnosis as early as possible, and some evidence shows that appropriate early intervention improves outcomes. In addition, genetic advice can be given at a time when parents are planning their family.¹⁸

Autism, like other developmental disorders, does not meet the criteria for screening.^{19 20} However, surveillance by the parent-professional partnership and rapid response to concerns throughout the preschool years are recommended. Few studies have been done of the sensitivity of general developmental screens or specific screening tests for autism in total populations. In one such study, which used the CHAT test to screen a total population at the age of 18 months, primary care staff asked parents questions about pointing, showing, and pretend behaviours and tested the child for demonstration of these behaviours. At follow up, the specificity of the test was high (97%) but sensitivity was too low (35%) to allow recommendation for use as a screening test for the whole population.²¹ Most other "screening" tests for autism have been used in groups of children already at risk of developmental problems, in which both sensitivity and specificity are higher.

More severely affected children (in terms of both IQ and social communication) usually present in the preschool years (under 5 years) with language delay. Higher functioning children tend to have a behavioural led presentation at around 4 or 5 years or subtle social problems in later childhood. The national autism plan has suggested that all professionals in contact with preschool and school age children should have training in autism and the alerting signals that indicate possible autistic impairment (box 2).¹³ Professionals can then discuss with parents the possibility of a problem before referral to second tier services.

Concerns about more able children, or those with Asperger's syndrome or so called "high functioning" autism, may not develop until children are exposed to the greater social demands of the primary school environment (box 3).¹³ Some children may even have been thought to be well advanced in their development, because of their special interests or precocious vocabulary.

Regression

In approximately 25-30% of affected children, obvious stasis and sometimes clear regression of development occurs between 15 and 21 months of age. This can involve loss of word use (usually within the first 10 word stage) accompanied by social withdrawal, loss of eye contact and play interests, and sometimes change of sleep and eating habits. Onset of unusual behaviours such as overfocused looking at objects and flapping or other mannerisms may also be noted. However, in many such cases, a careful history reveals that development of social communication was subtly abnormal before the onset of regression, and the lost words may not have been used communicatively. A more significant regression may occur in a very small number of children (7-8%) aged over 2 years after nor-

mal language development beyond the level of two word phrases. The resultant pattern of behaviour is indistinguishable from autism of early onset and is usually associated with severe cognitive delay (also known as disintegrative developmental disorder). Regression of skills needs careful medical assessment, as neurodegenerative conditions, Rett syndrome, and epilepsy may present in this way. No evidence exists to show that regression is on the increase.

Assessment process

The purpose of assessment is to confirm the diagnosis, seek an underlying cause, assess strengths and weaknesses in the child and associated developmental and mental health impairments (comorbidities), assess family needs, and identify the resources to meet the needs. For preschool services, referral is usually to the child development team or centre. For the school age child the referral pathway is much less clear and may be to paediatric, child and family psychiatry, or learning disability services. This can result in different and uncoordinated pathways of care for child and family. Autistic spectrum disorders in younger children can be managed within a child development service, as the child and family have many features of care need in common with those with other developmental problems. However, what makes autism different is the great variation in presentation, the wide range of skills and deficits, and the high rate of associated behavioural, mental health, and often subtle learning problems—hence the need for a range of available professionals. Diagnosis of autistic spectrum disorders should be as local to the child and family as possible, and all districts need to develop specialist expertise. Diagnosis is by history taking, focusing on the developmental story and systematically inquiring for core behaviours, and by observation in several settings. Box 4 outlines the common differential diagnoses.

Several instruments have been developed for history taking and play based observation of the child—the autism diagnostic interview and the diagnostic interview for social and communication disorders (both semi-structured interviews) and the autism diagnostic observation schedule (a play based interactive assessment used in both clinical practice and research).^{22–24} Box 5 summarises the medical assessment and investigations.²⁵ Associated features—developmental, neuropsychiatric, and medical—are common (box 6).

What happens after assessment?

The forthcoming national service framework for children emphasises a shift to child and family centred services. After assessment and explanation, a written report for parents and all relevant professionals is provided by the assessing team. Further investigations are indicated for some children. An action plan for the family should be produced. This includes access to information (websites, parent groups), parent training (for example, Early Bird²⁶), strategies for family support (a keyworker role is likely to be a recommendation of the national service framework), and an action plan for the child. Parents are clear about what they want from the process of engagement with services (box 7).

Box 4: Common differential diagnoses

Mental retardation or general learning disability

Differentiating autism plus learning disability from learning disability alone may be difficult in very young or profoundly delayed children; lack of imitation, poor social relatedness, eye gaze, and gestures indicate autism

Language disorder

Children presenting with receptive language problems may also have limited imaginative play skills and social impairment with peers

Other specific developmental disorders

Although thought to be particularly associated with Asperger's syndrome, clumsiness or incoordination (developmental coordination disorder) can occur in any of the autistic spectrum disorders

Other disorders causing diagnostic difficulty

- Reactive attachment disorders of childhood after early emotionally depriving experiences, such as those in Romanian adoptees, may present overlapping behaviours but also differences from autism²³
- Early onset epilepsy, Rett syndrome, or neurodegenerative disorders

Although research supports the effectiveness of a range of interventions, no evidence exists to show that one approach is more successful than others.²⁷ The emphasis has been on the effectiveness of behavioural and educational approaches, and some evidence is emerging that targeted interventions should begin as early as possible. The educational programmes that have tended to be most effective for young children with autism are those that

- Take account of the characteristic behavioural patterns of children with autism, showing an understanding of what may underlie those behaviours
- Use a structured, visual approach to teaching
- Focus on the development of specific skills and on increasing social communication and understanding
- Foster integration with peers.

Evaluation of intervention

A wide variety of interventions have been advocated for children with autism; these include Lovaas (applied behavioural analysis) programmes, use of pictures for expressive communication (as in the picture exchange communication system), intensive exercise pro-

Box 5: Medical assessment

- Detailed medical and developmental history
- Examination, including Wood's light, dysmorphology
- Routine hearing and vision testing, with further audiological investigation if any doubts about hearing
- Test for lead when history of pica
- Full blood count or film for iron deficiency when dietary habits limited
- Chromosomes for karyotype and fragile X where significant language delay or learning problems. Offer of genetic counselling
- Rett gene when learning difficulties, regression, or abnormalities suggestive of broader phenotype
- Consider thyroid and phenylketonuria tests if unlikely to have had these at birth
- No evidence for electroencephalography routinely in autism, but be alert to fluctuant symptoms and use as clinical tool in evaluation of epilepsy
- Neuroimaging only for specific neurological signs; focus on electroencephalography (sometimes) or triad of severe learning disability, autism, and epilepsy²⁴

Box 6: Associated developmental and mental health impairments (comorbidities)

- Studies have suggested that 75% of children diagnosed as having autism will have some learning difficulty. The current figure of 20-25% without learning difficulty may well be an underestimate; the figure is likely to increase as higher functioning children are increasingly given a diagnosis of autism
- Specific learning difficulties of attention, processing speed, working memory, and other tasks often thought of as executive skills are often impaired in autistic spectrum disorder and contribute to the common observation of a gap between structured test results where no or few problems are shown and daily functioning in real life where marked impairment is found
- Writing difficulties can create a major barrier to output for many high functioning children. Increasingly, the use of a laptop computer gets around a problem that often threatens to affect the attitude of the child to the entire educational process
- The lifetime risk of epilepsy is increased. Early studies suggested that up to a third of children with autism will develop epilepsy either in early childhood or in adolescence (many had learning difficulties, and more recent estimates suggest that prevalence is lower—about 17%)
- Learning disabilities in general are a risk factor for behavioural problems; 41% of children with mild to moderate or severe learning difficulties have severe emotional behavioural disturbance. Children with autism have double the rate of “caseness” of psychiatric disorder compared with those with learning difficulties⁴⁵
- In high functioning autism the risk of psychiatric disorders is also increased. In a Canadian study 17% of such children were more than two standard deviations above the population mean for attention deficit hyperactivity disorder and depression, as were 13.5% for anxiety. Other problems of motor coordination, sleeping, eating, and elimination are also more common in autism⁴⁴
- The association with abnormalities of bowel function awaits further research

grammes (for example, Higashi), and many other complementary techniques. Therapists, usually funded by the health service but increasingly working in educational settings, are under pressure to show the effectiveness of therapeutic input. However, as with so much of a child's educational experiences, outcomes are difficult to measure. Schools now recognise the holistic learning needs of the child, including personal and emotional growth as well as opportunities to broaden their experiences, regardless of whether measurable developmental progress is made.

Box 7: What parents want

- Equality of access and prompt response to concerns with clear, agreed care pathway or guidelines; sensitive diagnosis by competent professionals; accurate and relevant information; appropriate investigations
- Prompt provision of educational and therapeutic interventions (including behavioural strategies) that address functional impairments and teach through understanding of the effect of autism on the child's learning
- The streamlining, by multi-agency agreement, of assessment processes to ensure that children are not subjected to repeat assessments and families are not continually asked to repeat the same emotionally difficult information
- The introduction, alongside family held records, of a family support plan and services such as timely respite and sibling support groups
- The introduction of a keyworker or care coordinator where appropriate to guide families through the service maze
- Continued access to appropriate services through a convenient access point throughout childhood and adolescence (for example, mental health services) and smooth transition to adult services if needed

All children have a right to teaching and therapy geared towards improving their quality of life or potential. Professionals should use outcome measures to ensure a constant monitoring of the content and mode of delivery of services. Meaningful evaluation of intervention for children with autistic spectrum disorder is complicated by the need for individualised outcome measures. Any of the outcomes in box 8 may be considered the successful result of intervention.

Ongoing care

The manifestations of autism change with time and depending on other developmental impairments, personality, and the addition of medical or mental health problems. As with all developmental and learning disorders, children with autistic spectrum disorder and their families are as sensitive to the effects of other risk factors in family life as any other child and family. Some evidence shows that the failure to develop communication skills is a particular risk factor for parental stress.

Box 8: Possible outcomes for measuring the success of therapeutic and teaching interventions

- Normal use of verbal language (all pragmatic language functions met—for example, social use, needs met)
- Some use of verbal language for a range of purposes (restricted to some contexts, perhaps prompt dependent)
- Some functional use of language (for example, making requests, indicating needs (this may be spontaneous or prompt dependent))
- Ability to use an alternative or augmentative system of communication (this may be with or without adult support)
- Parents, carers, and teachers are better able to understand the child's idiosyncratic communication in order to care for his or her needs effectively—for example, in children with severe cognitive impairments

Young people who manage well until they develop epilepsy that is difficult to control may undergo considerable change in adaptive skills. Similarly, a young man who develops an acute anxiety or obsessive compulsive disorder in his adolescent years may have needs for services very different from those anticipated. Easy access to changed service provision is an aim of good practice.

Outcome studies in autism suggest that the disabling features and cognitive style are life long and that IQ, particularly verbal IQ, is a powerful predictor of future ability to undertake a job and live independently.²⁸ Associated psychiatric disorders can be successfully treated with drugs—for example, selective serotonin reuptake inhibitors for obsessive compulsive disorder and anxiety. Other strategies, including cognitive behaviour therapy, are less well researched, but some evidence shows that both cognitive behaviour therapy and the use of social stories can be of benefit, as can social skills training.

What makes autism challenging for services is that the range and level of function is so variable (although

core features are similar in all) and thus the service needs range across every type and place of service provision available. It is common to meet an adolescent with measured IQ in the normal range but whose functional adaptive skills are in the learning disabled range. Schools attended by children with autism range from mainstream through to highly specialised 52 week boarding facilities. Multi-agency, lifelong integrated care is the challenge. The aim of professionals should be to meet the changing needs of parents and children at all ages and stages. See bmj.com for a suggested care pathway for children with autism and their families.

Contributors: GB is the primary author. HC and VS contributed to all aspects of the review.

Competing interests: None declared by HC and VS. GB has acted as an expert witness in cases about the needs of children with autism (but never in diagnostic disputes).

- Wakefield AJ, Murch SM, Anthony A, Linnell J, Casson DM, Malik M, et al. Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet* 1998;351:637-41.
- Fombonne E. Is there an epidemic of autism? *Pediatrics* 2001;107:411-2.
- NHS immunisation statistics, England: 2001-02. www.doh.gov.uk/public/sb0218.htm
- Fombonne E, Cook EH. MMR and autistic enterocolitis: consistent epidemiological failure to find an association. *Mol Psychiatry* 2003;8:133-4.
- Fombonne E. The epidemiology of autism: a review. *Psychol Med* 1999;29:769-86.
- Szatmari P. The causes of autism spectrum disorders. *BMJ* 2003;326:173-4.
- Rutter M, Silberg J, O'Connor T, Simonoff E. Genetics and child psychiatry: II empirical research findings. *J Child Psychol Psychiatry* 1999;40:19-55.
- Veenstra-Vanderweele J, Cook E. Genetics of childhood disorders: autism. *J Am Acad Child Adolesc Psychiatry* 2003;42:116-8.
- Wing L. The continuum of autistic characteristics. In: Schopler E, Mesibov GB, eds. *Diagnosis and assessment in autism*. New York: Plenum Press, 1988.
- Wing L. Autism: possible clues to the underlying pathology: 1. clinical facts. In: *Aspects of autism—biological research*. London: Gaskell, 1988.
- Szatmari P. The classification of autism, Asperger's syndrome, and pervasive developmental disorder. *Can J Psychiatry* 2000;45:731-8.
- Fombonne E. The prevalence of autism. *JAMA* 2003;289:87-9.
- Le Couteur A, Baird G, National Initiative for Autism: Screening and Assessment (NIASA). *National autism plan for children*. London: National Autistic Society, 2003. Available at www.nas.org.uk/profess/niasa.html
- Howlin P, Moore A. Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism: Int J Res Pract* 1997;1:135-62.
- Osterling J, Dawson G. Early recognition of children with autism: a study of first birthday home video tapes. *J Autism Dev Disord* 1994;24:247-59.
- Charman T, Baird G. Practitioner review: diagnosis of autism in 2-3 year old children. *J Child Psychol Psychiatry* 2002;3:289-306.
- Stone WL, Lee EB, Ashford L, Brissie J, Hepburn SL, Coonrod EE, et al. Can autism be diagnosed accurately in children under three years? *J Child Psychol Psychiatry* 1999;40:219-26.
- Simonoff E. Genetic counselling in autism and pervasive developmental disorders. *J Autism Dev Disord* 1999;28:447-56.
- Cochrane A, Holland W. Validation of screening procedures. *Br Med Bull* 1969;27:3-8.
- Hall DMB, Elliman D, eds. *Health for all children*. 4th ed. Oxford: Oxford University Press, 2003.
- Baird G, Charman T, Baron-Cohen S, Cox A, Wheelwright S, Drew A. A screening instrument for autism at 18 months of age: a six year follow up study. *J Am Acad Child Adolesc Psychiatry* 2000;39:694-702.
- Lord C, Rutter M, Le Couteur A. Autism diagnostic interview—revised. *J Autism Dev Disord* 1994;24:659-86.
- Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The diagnostic interview for social and communication disorders: background, inter-rater reliability and clinical use. *J Child Psychol Psychiatry* 2002;43:307-25.
- Lord C, Risi S, Lambrecht L, Cook EH Jr, Leventhal BL, DiLavore PC, et al. The autism diagnostic observation schedule—generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord* 2000;30:205-2.
- Rapin I. Appropriate investigations for clinical care versus research in children with autism. *Brain Dev* 1999;21:152-6.
- Sheilds J. The NAS EarlyBird programme: partnerships with parents in early intervention. *Autism: Int J Res Pract* 2001;5:49-56.
- Howlin P. Practitioner review: psychological and educational treatments for autism. *J Child Psychol Psychiatry* 1998;39:307-22.
- Howlin P. Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism: Int J Res Pract* 2000;4:63-83.

A parent's perspective

Public awareness of autism has increased over recent years, yet early recognition of autism remains variable. As a therapist with several years' experience in child development, I became concerned during my son's first year about his social development and play skills. He never pointed, and after some language regression (from 30 to six words) occurred at 18 months autism crossed my mind. I discussed this with the health visitor at his 18 month check. I received reassurances, and his language development was marked as "satisfactory—single words." I insisted on a referral for speech therapy when he was 2½. He was assessed and diagnosed as "a late talker" by a therapist who, we later discovered, worked with adults. His inability to settle in nursery prompted me to compile a list of all my concerns. I went to my general practitioner and pleaded for a referral to the local child development centre. My son was diagnosed as having an autistic spectrum disorder at the age of 3 years and 3 months.

Diagnosis is often seen as enabling access to appropriate intervention and support. In reality it means being added to existing waiting lists for already overstretched services. My son ceased to be viewed by professionals as a child and was discussed as a problem to be managed. Our parents found it hard to accept that "the right help" wouldn't cure him. I was deemed "too negative" for pointing out that this is a lifelong condition. We received a deluge of material about autism and interventions, mainly downloaded from the internet.

My son's preschool provision consisted of advice from a teacher-parent counsellor (one hour a fortnight, term time only), a helper funded for nursery (three mornings maximum, no training provided), speech therapy (initial six sessions and periodic follow up), and an invitation to join the pilot Early Bird course that autumn term. When Early Bird started, my son had his specialist input withdrawn for the duration of the course (in reality July-February). We decided to make alternative private provision, funding an applied behavioural analysis programme costing over £20 000 a year. We also paid for private speech and language therapy. He now attends an autism resource base within mainstream education, in an adjacent borough. Getting the local education authority to agree was a struggle, and there are ongoing problems.

We have had mixed experiences with the medical profession. We have a very knowledgeable and supportive local paediatrician. Our local general practitioners have shown great patience and understanding when treating my son for minor ailments. He is now a highly verbal and anxious 6 year old, who insists on examining the doctor before he himself is examined. However, as a 4 year old he had a fractured tibia and fibula. Neither the junior emergency staff nor the orthopaedic team knew what autism was. One doctor wrote "severe learning difficulties" in his notes. Another asked me what his particular savant skill was, as she had seen *Rain Man*.

Raising a child with autism is a challenge. We are not searching for a cure, just the best possible education to help him reach his potential. I have the professional experience that allows me to understand his difficulties. We are in a financial position to supplement local provision. In many ways we are fortunate; other families are not so lucky.

Additional educational resources

- Attwood T. *Asperger's syndrome: a guide for parents and professionals*. London: Jessica Kingsley, 1988
- Baron-Cohen S. *Mindblindness: an essay on autism and theory of mind*. London: MIT Press, 1995
- Baron-Cohen S, Bolton P. *Autism: the facts*. Oxford: Oxford University Press, 1993
- Frith U. *Autism and Asperger's syndrome*. Cambridge: Cambridge University Press, 1991
- Jackson L. *Freaks, geeks and Asperger syndrome*. London: Jessica Kingsley, 2002
- Wing L. *The autistic spectrum: a guide for parents and professionals*. London: Constable and Robinson, 2002

Useful website

National Autistic Society (www.nas.org.uk)—provides information about autism and Asperger's syndrome and about support services available to people with autism, families, and professionals