Recognition and treatment of Asperger syndrome in the community

Digby Tantam†‡* and Sobhi Girgis†

†Department of Psychiatry, University of Cambridge, Cambridge, UK; ‡Centre for the Study of Conflict and Reconciliation, University of Sheffield, Sheffield, UK, and *Sheffield Health and Social Care Trust, Sheffield, UK

Sources of data: We conducted a systematic review of the current literature for this review, but as there are many gaps in the research literature, we have supplemented this by our own clinical experience.

Areas of agreement: There is a general agreement that Asperger syndrome (AS) is one of the autistic spectrum disorders, that it is a developmental disorder which is either present at birth or develops shortly after and that there is a strong hereditary component.

Areas of controversy: The fundamental impairment of AS is in the social arena, but what causes this is disputed. We propose that it is a disorder of non-verbal communication. Another important area of controversy is the extent to which AS may remit.

Growing points: Many people with AS develop secondary psychiatric disorders in adolescence and adulthood, some of which may be linked genetically, notably bipolar disorder [DeLong R, Nohria C (1994) Psychiatric family history and neurological disease in autistic spectrum disorders. Dev Med Child Neurol, 36, 441–448] or be explicable by some other association, but many patients and carers attribute their anxiety and low mood to bullying. The prevalence, treatment and prevention of co-morbid mental health problems are rapidly developing areas of interest. Some people with AS are known to commit offences, and when they commit they are more likely to be violent offences against strangers. How much of a risk that is presented by people with AS, and how to assess this risk, is another growing area of concern.

Areas timely for developing research: The social impairments of people with AS include deficits in empathy, self-awareness and executive function. Many of these are quintessentially human characteristics, and the study of people with AS provides opportunities for using neuroimaging to compare people with AS and controls and identify which areas of the brain are concerned with these ‘higher functions’. The study of AS, like that of other fronto-striatal disorders, is also throwing light on the role of networks in the brain and on how networks are formed during embryogenesis.

Keywords: Asperger/diagnosis/detection/community/treatment/management
Introduction or background

Autism, Asperger syndrome (AS) and the MMR (measles, mumps and rubella) vaccine have become headline news nowadays. The prevalence of identified autism and identified AS have increased dramatically, especially the latter, perhaps as much as 11 times. Even though there has probably not been an actual increase in the prevalence of the condition, and certainly not of this magnitude but an increase in recognition only, this greater recognition has led to many more of the public asking for help and advice about the condition. But what is AS and how does it fit with other childhood onset problems, such as autistic spectrum disorder (ASD), or pervasive developmental disorder (PDD), all terms that have recently become common in the field? What happens to children with autism when they grow up? What role does the general practitioner (GP) and the general psychiatrist have in helping people with autism or one of these related disorders?

We answer these and other questions in this review.

What is AS?

AS is named for the Viennese paediatrician Hans Asperger who described ‘autistische Psychopathie’ in 1944. It is now generally considered to be one of the several incompletely differentiated disorders on the ‘autistic spectrum’, a term first introduced by Wing and Gould. Asperger himself thought that he was not describing a separate syndrome from the ‘early childhood autism’ described by Kanner in 1943, although Kanner disagreed. Although ICD-10 and DSM-III-R introduced separate terms for AS in 1992 and 1987, respectively, repeated studies have failed to find criteria validating a differentiation other than the arbitrary cutoffs included in the diagnostic criteria. These exclusion criteria are: (i) delay in cognitive development (and by implication of mental handicap); (ii) language delay (and by implication of either mental handicap or specific language impairment or both); (iii) onset in the first 3 years of life (DSM-IV only); (iv) absence of criteria for making another diagnosis, with a variety of disorders including simple schizophrenia being specified.

We advocate the view that there is one, or possibly two, core autistic or pervasive developmental impairments which are present in everyone on the autistic spectrum, but that many people on the spectrum have additional impairments and it is these that distinguish AS from Kanner syndrome.
Core autistic impairment(s)

The triad of social impairments (see Box 1) has been the basis for the diagnosis of ASDs for over a decade, even though many of its constituent elements are hard to define, sometimes inconsistent and rely on observational judgements that have not been standardized or validated. Its values are comprehensiveness and its support of a family resemblance approach to diagnosis. This allows for the considerable variation in presenting symptoms of people with AS even when allowance is made for the presence of co-morbid impairments.

Box 1  The triad of social impairments.

Consists of impaired

- comprehension and use of communication, both verbal and non-verbal;
- two-way social interaction;
- true, flexible, imaginative activities, with the substitution of a narrow range of repetitive, stereotyped pursuits.

One of us has argued consistently since the mid-1980s⁵ that the core autistic impairment is an impairment in non-verbal communication. Other candidates for the core impairment have been put forward in the past—language impairment by Rutter, for example, or anxiety by Tinbergen—but none have stood the test of time in the way that impaired non-verbal communication has. Recent studies of early diagnosis have also supported impaired non-verbal communication as being one of the best predictors of a later diagnosis of autistic disorder.

Non-verbal communication means the use of gesture, posture, gaze direction, voice prosody, use of space and facial expression to communicate mental contents, such as thoughts and feelings. It overlaps with pragmatics, or the shaping of speech or writing by the needs of the audience or the desire of the speaker or writer to influence the audience in a particular direction.

Only a small part of non-verbal communication involves sending or receiving explicit messages, such as forced, social smiles or conventional gestures like waving. Most of it is automatic in that it occurs without the mediation of planning or self-reflection. Verbal phrases or sentences, in contrast, are formulated from a conscious process of ‘framing’ a thought, although in practice there is an admixture of non-verbal and verbal communication in any particular utterance or statement.

Both verbal and non-verbal communications include an element of encoding and of decoding. People with AS who have a substantial
difficulty in encoding non-verbal communication, that is in non-verbal expression, fit best with many people’s mental picture of a person with AS. Their manner may appear odd, because of gait, gestural or postural idiosyncrasies, their speech may not seem tuned in to the listener and may, therefore, make them seem self-preoccupied or eccentric, and their lack of or idiosyncrasies in facial expression may further frustrate social expectations. Prosodic impairment in speech is often now linked to speech dyspraxia and it may be that these non-verbal encoding difficulties are a reflection of the dyspraxia with which this presentation of AS may be associated.

Many people with this kind of AS also have decoding impairments. They find it difficult to read faces, for example, or to infer what another person is thinking from the direction of their gaze. This may be due to a very early failure, indeed perhaps the original psychological impairment to orientate the eyes, and to their direction of gaze. It is not clear whether these impairments in non-verbal interpretation amount to a second core impairment, or whether there is a more general impairment of both encoding and decoding, as is the case for verbal communication in Wernicke’s aphasia and a second, more specific disorder of decoding, comparable to Broca’s aphasia in verbal communication.

Our clinical experience is that there are important differences between those whose main impairment is in decoding, that is, an impairment of non-verbal interpretation, and those with a combined expressive and interpretative impairment. In the absence of an accepted diagnostic category, we have termed the former as ‘atypical AS’.

An impairment of non-verbal interpretation leads to a lack of empathy (not to be confused with a lack of sympathy, that is, with a lack of compassion—that may or may not be affected). This does not just prevent a person from taking other people into account on every occasion when to do so is expected; it also reduces a person’s persuasiveness leading to a loss of social influence, which can increase social isolation and frustration. Atypical AS is, in our clinical experience, more likely to coexist with attention-deficit disorder (ADD) and attention-deficit hyperactivity disorder (ADHD) or with dysexecutive syndrome in the absence of other symptoms of ADD, with specific expressive language impairment, and with Tourette syndrome.

Many people with AS will describe themselves as having friends, but close enquiry often reveals that these are what others would call acquaintanceships or sometimes one-sided friendships. An increasing number of people with AS are making friends because more opportunities are available. People with atypical AS may make friends easily with their age group, unlike people with typical AS, but do not keep...
them, as they are unaware of how to maintain the friendship through symmetrical relationship building (Argyle, 1967).

The lack of peer relationships, coupled with the comfort to be received from routine and a desire for eradicating uncertainty through systematization, can often lead people with AS into espousing unusually narrow, private interests (‘special interests’). These are less developed and, therefore, less easily noted in people with autism, often become dilapidated as the energy goes out of them in older people with AS and are often concealed in people with atypical AS who are particularly committed to trying not to be different from their age group.

We show some of the distinguishing features of these two types of AS, and of childhood autism, in Table 1.

### The commonsense approach to AS

Although there may be little scientific distinction to be made between AS and other ASDs, there is an important functional difference, recognized by carers and people with AS, which has necessitated the development of separate educational, health and social care for people with AS. This difference may become particularly acute in adolescence, which is often more distressing and stormy for people with AS than for people with autism. Parents often put this down to their son’s or daughter’s ability to compare themselves with others, implying that their child has sufficient awareness of their own and of other people’s lives to be able to see the ways in which their own could be improved. Research supports the parents’ perception. People with autism have an impairment of their ‘theory of mind’, that is, their ability to account for the idiosyncratic knowledge, experience and point of view that each actor has in any social situation. This impairment of ‘theory of mind’, which may be due more to the language impairment than to the autistic impairment, affects a person’s own ability to recognize that they have a point of view as much as their ability to recognize other people’s. It is closely linked to the increasingly important medico-legal concept of ‘capacity’, which includes the ability to formulate one’s own best interests.

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Recognition and treatment of AS in the community
The commonsense use of AS is to apply the term to a person on the autistic spectrum who has the capacity to make decisions for themselves and who also has the capacity to recognize their difference from other people and some of the consequences of this, which are regretfully often adverse and, therefore, emotionally distressing.

**Diagnosis**

Impaired non-verbal communication may not be easy to spot, and if recognized in a global judgement of ‘oddity’, it requires conscious effort to categorize it. Transient impairments of non-verbal communication may occur in anger and more lasting ones in depression. These are not due to impaired capacity, but in impaired performance. Impaired capacity for non-verbal expressiveness, and possibly for non-verbal interpretative ability, may occur in long-standing schizophrenia, where they form a part of the negative syndrome. The one-off assessment of non-verbal communication may, therefore, be sensitive to a diagnosis of an ASD, but is not specific to it. Its absence should, therefore, call a diagnosis of AS into question and its presence should be supplemented by other diagnostic criteria before making a definite diagnosis (see Box 2).

**Box 2** A flowchart for differentiating the PDDs.

Is there an impairment of non-verbal communication? Then

- if there is clear history of normal development until the third year of life, and epilepsy precedes or accompanies cognitive deterioration, consider disintegrative disorder;
- if there is generalized learning disability or a disorder of language as well as speech, consider autistic disorder;
- if there is a history of cognitive or language delay which has been overcome, make a research diagnosis of autistic disorder, but consider telling the patient and the carer that they have high-functioning autism or ‘AS’;
- if there is a lack of empathy out of proportion to other impairments, consider a diagnosis of ‘atypical AS’;
- if there is a clear developmental history of the triad, consider a diagnosis of AS, otherwise consider PDD not otherwise specified.

Important supplementary diagnostic criteria are: (i) evidence that the disorder began early in life (before the age of 3 is specified by ICD-10) and (ii) an impairment of everyday social interaction. Supportive
evidence is provided by avoidance of change, cleaving to routines, special interests, a history of incoordination or topographical disorientation, motor stereotypes, unusual sensory behaviour (hypersensitivity, unusual fears or fascinations with sound and absorption in one sensory experience to the exclusion of all others) and pragmatic errors in language including concrete use of language, a lack of understanding of jokes that require paralinguistic cues or ‘commonsense’ to be applied, inability to understand idioms, inability to change idiolect to suit social setting (sociolinguistic impairment), problems with pronouns and other ‘shifters’ and the boiler-plating of catch or imitated phrases into conversation without, apparently, fully understanding them.

Prevalence

The inclusion of AS in the PDDs, changing diagnostic criteria and greater awareness make it difficult to compare the prevalence rates over time. Fombonne has formerly concluded in a review of what is now a substantial literature that it is unlikely that there has been no real increase in the condition itself, only its recognition, but in his most recent summary (ibid.) concludes that ‘Autism has a strong genetic basis but the possibility of additional causal environmental risk factors remains...If environmental risks contribute to the increase in incidence, their impact must occur at or shortly after conception but no solid clues are yet available’. There is a strong public perception that there has been a substantial increase, and exposure to the MMR vaccine has been blamed. Despite repeated investigation having failed to find an association, this led to a fall in uptake in routine childhood vaccination and is reflected in a growing demand for specialized education. Epidemiological studies conducted in different countries have shown more or less comparable prevalence rates for ASDs. A recent meta-analysis of 40 studies estimated a prevalence rate of 7.1 per 10 000 for autistic disorder itself and 12.9 per 10 000 for all other ASDs, including AS. Confidence intervals were wide, and a meta-analysis of US studies with a total base population of over 400 000 8 year olds concluded that ASD affects a higher proportion of 8 year olds: 1 child in every 150. The latter is the rate currently used by the UK’s National Autistic Society. This rate is comparable to the prevalence rates for PDD of 3.1–6.0 per 1000 children found in two recent European studies.

Rates of AS are more difficult to come by because there remains considerable controversy about the distinction between AS and the so-called ‘high-functioning’ autistic disorder. In one large Finnish study, of 5484 8 year olds, this problem was addressed by using four
different diagnostic criteria. There was good agreement between three of these, including DSM-IV and ICD-10. Averaging the three convergent rates provides an estimate that AS affects 1 in every 370 children aged 8 years.\textsuperscript{17}

It is usually assumed that the PDDs are life-long disorders and it would, therefore, follow that the prevalence of PDD in adults is the same as that in children. This would mean that every GP in the UK with a list size of 2000 might have 13 patients with a PDD, and every general psychiatrist with a catchment area of 50 000 might have 68 patients with PDD and a normal IQ in their patch. However, there is some reason to doubt the presumption that there can be no recovery. Asperger himself reported in a talk to the National Autistic Society of the UK in 1970 that many of the children that he had diagnosed ‘had a good prognosis’ and attributed it to the effects of education. His daughter (M. Asperger, personal communication) has explained to one of us that her father provided these children with an intensive hospital-based programme of therapy and education (perhaps similar to that provided in some adolescent units today), and that it was the combination of psychotherapeutic and educational methods that was beneficial.

A recently completed survey of Sheffield adolescents and adults with AS\textsuperscript{18} found a progressive fall in the estimated prevalence with age in males with AS, which was too substantial to be likely to be accounted for by increased mortality or institutionalization in the Asperger group but was suggestive of remission in a proportion of children with AS. The fall in prevalence was shown only in males: AS was just as prevalent in older women as in teenagers, although at a lower rate than in boys and men.

Autism is more prevalent in males than females with a ratio of 3:1 or 4:1. In studies using broader definitions,\textsuperscript{9} the ratio is reported to vary linearly with IQ reaching up to 10:1 in the more able group. In the Sheffield survey (\textit{ibid.}), the overall ratio of men to women was 4:1. Just under a half (43.5\%) of the surveyed sample had never had a diagnosis. The male:female ratio in this undiagnosed group was much lower (1.8:1). This suggests that male gender increases the chances of diagnosis, and that AS in women is underdiagnosed, possibly because of the hypothesis recently put forward by influential researchers\textsuperscript{19} that AS is an extreme form of maleness. It also suggests that diagnostic practice currently has an inbuilt gender bias.

The failure to diagnose, or to diagnose sufficiently early, remains the greatest concern of carers because of its ramifications for understanding, services and treatment (see Box 3).
**Box 3** Consequences of failure to diagnose.

In children
- Absence of early intervention
- Family without an explanation of difficulties
- Inappropriate schooling
- Unawareness of risk of social, emotional and behavioural problems.
- Failure to provide genetic screening

In adults
- Family distress/spousal distress
- Failure to meet social and emotional needs: work support, social inclusion, benefits entitlement/use of community resources, support in child care
- Failure to divert affected offenders from imprisonment to a therapeutic disposal

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**Co-morbidity**

**Medical**

There is an increased association between having an ASD and a variety of other medical conditions (see Boxes 4 and 5). The likelihood of having a diagnosable co-morbid physical condition is greatest for autistic disorder and least for AS.

**Box 4** Medical conditions reported in association with AS.

1. Tuberous sclerosis
2. Neurofibromatosis
3. Hypothyroidism
4. Congenital deafness
5. Congenital visual impairment
6. Epilepsy
7. Neuromuscular disorders
8. Connective tissue disorders affecting muscle function
9. Hereditary disorders affecting glucocorticoid levels
10. Fragile X syndrome
11. Sotos syndrome
12. A variety of chromosomal disorders
Box 5  Key points.

Autistic disorder, Asperger syndrome (AS) and other pervasive developmental disorders shade into each other.
Current evidence is that they are all neurodevelopmental disorders with a strong hereditary component, but only Rett syndrome has a known cause.
People with AS are prone to emotional problems and this may reduce their quality of life below that of apparently less able people on the autistic spectrum.
Early diagnosis and early intervention can produce a reduction in the impairment caused by the condition and can probably reduce the emotional consequences of the disorder both for the sufferer and for their families and carers.
The GP is still the first professional that many families consult about diagnosis.
In children, developmental delays in socialization, language and motor coordination and, in adults, a life-long difficulty in making friends indicate the need for further assessment for ASD.

Epilepsy is more likely in people with AS than in the general population, although reported rates vary, possibly because the definition of epilepsy also varies. Fits, when they do occur, are more likely to be complex than in the total population of people with epilepsy and in at least some cases may be due to temporal lobe scarring. Temporal lobectomy rarely reduces the severity of the autistic spectrum symptoms.

Neuropsychological

There is an increased risk of developmental dyspraxia in people with AS, perhaps particularly in the most typical group. Dyspraxia is a clinically mixed syndrome. Some affected individuals may have impaired topographical orientation, but other people with AS may be excellent with maps and in memorizing routes. Fine motor control may be impaired but not always. The most constant finding is impairment of whole body coordination, often affecting eye–hand coordination and in younger children, dressing, shoelace tying and other tasks requiring bilateral coordination.

There is an increased risk of ADD and disorders that are associated with ADD and ADHD, such as dyslexia, specific language impairment and Tourette syndrome. Dysexecutive impairment may occur in the absence of the other elements of ADD. This may manifest in
reduced working memory, reduced ability to plan and budget, an inability to multi-task because of an inability to ‘keep one’s place’ in an ongoing task that has been put on hold and a reduced ability to carry sequential tasks. Dysexecutive syndrome may be subtle and easily missed, but can have disabling effects on everyday living.

**Psychiatric**

In our own unpublished series of cases seen in our clinic (amounting to some 1200 people), schizophrenia is no more common than that would be expected, but bipolar disorder is more common as is, probably, obsessive–compulsive disorder. Obsessive–compulsive disorder with characteristic ego alien compulsions can usually, but not always, be distinguished from the rituals and routines that many people with AS considered valuable ways of dealing with uncertainty. Depression may be more common, although the shifting diagnostic criteria and its frequency in the general population make it uncertain, how much more common it is. Anxiety and anxiety-related disorders, of clinically significant severity, have been diagnosed before presentation in over 40% of our clinical attenders. Although the life-time risk of anxiety-related disorders is high, most of those attending our clinic are in their teens and early 20s and this rate is likely to be elevated. In our series, the type of anxiety disorder reflects the age at which the anxiety develops and to some degree, early experience. Dysmorphophobia—a self-critical preoccupation with the size or shape of a bodily part—is often overlooked, but may be an early reaction to the growing perception for some people with AS of being the odd one out. Anorexia nervosa and agoraphobia may also occur, but social phobia is probably the most common anxiety-related disorder, and may contribute to social withdrawal and a lack of social practice that may otherwise ameliorate social impairment. Clinical experience suggests that the risk is increased by bullying and victimization.

In our experience, deliberate self-harm, suicide and substance abuse—all of them particular problems in adolescence—are less common in adolescents with AS. However, they may all occur and should not be forgotten. Alcohol abuse may be more common in older adults with AS.

Catatonia occurs in ASD rarely but possibly more commonly than in the general population. We have had occasional cases in AS, too. It is sometimes neglected because it is considered as an extreme manifestation of AS by professionals. Benzodiazepine treatment appears to be effective, but has not been systematically evaluated in people with catatonia and AS, and needs to be so. The causes of catatonia are
unknown but the efficacy of benzodiazepines suggests a link with anxiety. Cycloid psychosis, originally described by Kleist as ‘anxiety psychosis’, may also occur more commonly in people with AS, at least judging by our own case series. The presentation is of a rapid onset, florid psychosis in which there may be first rank symptoms, but which usually resolves quickly, sometimes with a low dose of antipsychotics.

**Experience of AS**

The experience of autism is very variable depending on age, language development and intelligence. However, everyone with autism seems to find making close friends difficult, the social world threatening and change unpredictable and upsetting. Many people with autism live with high levels of anxiety, much of the time. People with autistic disorders do not get latched into the normal socializing process that other infants do, perhaps because of an inborn failure of social relatedness due to their impaired non-verbal communication. As a result they discover the world afresh and this can lead to striking idiosyncrasy and originality as well as unexpected errors in social judgement. People with autism often seem to live in a world of their own and may describe themselves as ‘different’, lacking some sense that others have, or as being behind a pane of glass. Contrary to common misperception, many are sociable and want to make friends, failing to do so only because of a lack of intuition about how to behave as a friend. The internet has changed the lives of many people with autism, since it offers new possibilities of social interaction, which are not so reliant on non-verbal communication.

**Social and emotional problems**

People with autism encounter negative social experiences of isolation and marginalization. Bullying at school is very common, and its emotional impact may persist into adulthood. These difficulties are most strongly felt in the ‘high-functioning’ group. In the UK, members of this high-functioning group are often said to have AS even if they have had cognitive or language delay in the past.

Perhaps as a result of their reflection on the injustice of their social isolation, people with AS may experience depression or anxiety-related disorders, such as anxiety states, social phobia, dysmorphophobia and panic disorder, and these disorders are often worse in adolescence and young adulthood.
Management

Diagnosis is the first, and possibly the most important step, in management. The GP should suspect autism in any child with delays in language, socialization and motor development. The general psychiatrist should suspect autism in any adolescent or adult who has never had close friends. A history should be taken from parents and carers, and the observations of other health professionals should be taken into account. Final diagnosis will usually require a specialist referral.

The fundamental impairment in ASD is a subtle one, possibly because non-verbal communication rarely receives direct attention or comment. Parents or grandparents may often be the first to recognize that there is something wrong that profoundly affects their contact with the affected child. Health professionals find such non-specific complaints difficult to respond to and are reluctant to diagnose autism at an early age. More structured observations may help to make a diagnosis in the less able, more severely affected group. Retrospective analyses of home videos suggest that gaze behaviour is a particularly good clue, and this and other possible signs of autism have been included in the Checklist for Autism in Toddlers (CHAT) that has been trialled as a screening tool in general practice. The CHAT completed at 18 months of age was successful in correctly assigning 65% of autistic children, but did not reliably predict the later overt development of the symptoms of AS, suggesting that this diagnosis cannot yet be made reliable at an early age. A new screening test suitable for AS is currently under development.

Authoritative guidelines have been published in the last few years covering the screening, assessment and management of autism. The most recent in the UK are those produced by the Scottish Intercollegiate Guidelines Network, the Royal College of Psychiatrists and the National Autistic Society (the National Autism Plan for Children). The Royal College of Speech has produced guidelines about the provision of speech and language services, which include services for people with ASDs. Many of these guidelines, although they mention AS, have limited application to this condition and to adults in general. Similar documents have been produced in many other countries, for example that of the American Academy of Neurology. All of them conclude that clinical judgement continues to be the only reliable basis for diagnosis, although many suggest supplementary structured interviews that may be used, and the Scottish guidelines advise that close attention to either DSM-IV or ICD-10 criteria is advisable.

The American Academy guidelines notes that parent’s concerns about abnormal development are both sensitive and specific, although
an absence of concern should not be assumed to mean that the child’s development is normal. They recommend that parents should be specifically asked about developmental milestones: we would suggest that particular attention should be paid to social relatedness, language and speech and motor development. High-risk children, for example the siblings or children of people with autism, should be particularly carefully screened. The guidelines recognize that AS and some other PDDs may be missed at an early stage: we suggest that developmental screening should, therefore, be repeated at a later than normal date if parents have later concerns. Finally, the guidelines recognize that diagnosis requires the use of the whole clinical picture by an experienced professional.

Once diagnosis has been made, other co-morbid conditions also need to be screened for. The yield of intensive investigation is probably too low for invasive or time-consuming investigations to be carried out in the absence of a history of symptoms suggestive of the associated disorder being considered. However, a careful and systematic history should be taken from both the person with AS and an informant. Observation of the patient can occur alongside history-taking, and the observer should pay attention to any overt neurological signs, to skin lesions that might suggest tuberous sclerosis, to evidence of hearing or visual impairment, both of which may be associated with AS. CAT or MRI is not routinely justified, although should be considered if there are any neurological signs. An EEG will often show non-specific abnormalities but these are unlikely to be of clinical significance in the absence of seizures.

Psychometry, particularly IQ testing and testing frontal lobe function, can be useful in planning education and sometimes in advising about employment.

Intensive social training programmes in early childhood have had enthusiastic endorsements, although full independent evaluation remains to be carried out. The results suggest that if communication with an autistic child can be established, the child’s social development can be accelerated and sometimes brought back to its normal trajectory, despite the persistence of the underlying neurobiological abnormality.

Whether or not a child attends special school remains contentious, but what is clear is that a child with autism has special educational needs. These include having teachers who know how to communicate with an autistic person, attention to social and emotional understanding in the curriculum and an active programme of integration with other children, with close attention to detecting and combating bullying. People affected by autism and their families should be told the results of their assessment in language that they can understand, and
this should be followed up by a letter that can be used in future consultations. Counselling should be available for people with autism or their family members who have developed emotional problems as a result of the condition.

People diagnosed for the first time in adolescence or adulthood, and their carers, also need access to education about the condition. People with autism are often competent to make decisions and they should be consulted about the extent to which their carers will be involved in their health care.

Mental health problems are more common in people with autism. The emergence of psychotic symptoms in an individual with autism does not necessarily indicates the onset of a long-term psychotic illness, as brief psychotic episodes are not uncommon. Schizophrenia is rare in people with autism, and the most common recurrent psychosis is bipolar disorder, which also appears to be overrepresented in the families of people with PDD, especially AS. The most common mental health problem is depression or an anxiety-related disorder. People with AS are unusually sensitive to change and they may experience loss particularly acutely. It is worth considering an emotional problem whenever there is an otherwise unexplained deterioration in the behaviour or social functioning of a person with AS.

It is not uncommon that adults with undiagnosed AS present for the first time with domestic or occupational difficulties. Their social and emotional disability might cause considerable strain in their relationship with their partners at home or their colleagues at work. As parents, they might have difficulty in picking up cues of their children being upset, frightened or in pain. Their limited sociability is likely to limit the amount of social interaction their children would experience unless this is compensated for by other adult carers.

**Medication**

There is a naïve, but persistent, view that many people with ASDs can be helped by medication, and almost all of the classes of psychotropic drugs have been advocated with antipsychotics being particularly often recommended. Clinical trials sometimes seem to support the value of medication, but only if the placebo effect of trial involvement is not taken into account. We cannot recommend the routine use of any medication to treat AS. People with AS can sometimes experience a sudden rise in arousal that has similarities to the catastrophic reactions seen in dementia or after a cerebro-vascular episode. This can result in aggression, self-harm or other actions that put the person concerned or those around them at risk. Underlying depression may be a cause, in
which case it can be treated with an antidepressant or with cognitive therapy, but sometimes the cause simply seems to be an inexorable rise in subjective anxiety with an increasing desire for release. Sedative antipsychotic drugs and anticonvulsants have both been used to treat this condition, and some clinicians have found them to be effective in producing sedation and reducing the frequency of reactions. In the absence of evidence either for their effectiveness compared with psychological care or for how long they remain effective, they should be considered as a last resort, and their continuation should be regularly monitored.

The development of catastrophic reactions, an increase in stereotype or an increased difficulty with change or the re-appearance of behaviours from an earlier period of development should initiate an assessment for a co-morbid disorder, with particular emphasis on anxiety-related disorder. The usual symptoms and signs of anxiety or depression, such as poor concentration, new onset sleep disturbance, suicidal thoughts, onset or worsening of self-harm or complaints of feeling tense or low should, of course, also be taken seriously and followed through. If a diagnosis has been made, medication or psychological treatment should be recommended according to currently available guidelines for the co-morbid condition. In our experience, selective serotonin reuptake inhibitors are usually well-tolerated and effective treatments for anxiety and anxiety-related disorder when combined with psychosocial intervention. Antipsychotics are effective for the treatment of psychosis, but may not need to be maintained beyond the remission of symptoms if the sudden onset and high levels of anxiety suggest that the psychosis is of cycloid type. Many people with AS have some degree of phobia about medical intervention, and lithium levels may prove difficult to monitor. An atypical antipsychotic (in children) or semisodium valproate may be, therefore, preferable as a maintenance medication, although there is an absence of research in this area, and current guidelines should be consulted.

Empathy training, social skills training and desensitization to hyper-aesthesiae may all be effective in studies, but have yet to find a place in routine clinical practice. One reason may be that interventions even if effective in one setting may not generalize to others. An alternative strategy is to provide counselling or psychotherapy, which draws on behavioural, cognitive and re-training principles but does so in the context of solving real problems in everyday life.

**Mental health services**

The high prevalence of co-morbid disorders means that there will be a need for psychiatric input (for both the service and the individual)
together with a framework that ensures their close coordination. The services for people with AS remain patchy. There is lack of clarity as to where the disorder fits within the current structure of mental health services. Adults with the disorder could be deemed as not eligible for services from either adult mental health or, by virtue of their IQ, the learning disabilities services. The Royal College of Psychiatrists (2006) concluded that all psychiatrists should be able to recognize the syndrome, diagnosing it in clear-cut cases, and be aware of its implications. The College recommended postgraduate training at all levels from basic psychiatric training through to continuing professional development. For those cases where diagnosis is less straightforward, or where clinical management is more complex, there needs to be access to local specialist expertise and, where necessary, to tertiary specialist services. A governmental report (2006) suggested that people with ASDs who have received a service from CAMHS (Child and Adolescent Mental Health Centre) and do not fit the criteria for ongoing care in adult mental health should be discharged back to their GP when they reach 18 years. In a subsequent document (Department of Health, 2006), the government made it clear that the current position, whereby some people with an ASD ‘fall through’ local services, in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy. The report emphasized the importance of proper assessment, identifying needs and meeting those needs through the most competent approach rather than deciding on which service should provide all those needs, individualized care and social inclusion. The report encourages the provision of the new approaches to funding and support, such as direct payments and individual budgets to people with ASD in the same way as everyone else.

**Mental capacity and consent**

The Mental Capacity Act (2005) stipulates that a person is assumed to have capacity unless it is established that he/she lacks capacity. A person is not to be treated as unable to make a decision unless all practicable steps to help him/her do so have been taken without success.

The assessment of mental capacity of people with AS and the validity of their consent to treatment may be complicated by a number of features of the disorder. These include difficulties with comprehension which may be masked by an apparent good use of language, difficulties with attention and concentration, problems in coping with change leading to extreme aversion to anything new and an impaired ‘theory of mind’ resulting in a rigid unrealistic perception of how the world works. As we have already
said, people with AS normally have capacity. The most exception is, in our experience, when fear of change prevents a person with AS from accepting something new, even if that is in their best interests.

**People with AS coming in contact with the criminal justice system**

While many people with the disorder are reliable witnesses, AS can affect the ability of someone to give an accurate account of an event because of such factors as idiosyncratic misinterpretations of events, difficulties with time dimension, difficulties in distinguishing own actions from others’, inability to cope with formal interviews because of unfamiliarity, problems with understanding others and expressing themselves both verbally and non-verbally and consequently giving wrong statements or wrong impressions, undue compliance and a tendency to stick rigidly to their own accounts even if they were inaccurate. They might not be recognized as vulnerable adults because of their academic abilities. People with AS are by definition suffering from a mental disorder. Under the Police and Criminal Evidence Act 1984, they are entitled to have an appropriate adult present when they are interviewed by the police.

Some people with AS would, sadly, find the structured environment appealing. However, many are vulnerable people who find themselves in conflict with the structure and at risk of serious harm from others (Scottish Executive, 2004)

**Offending**

In the Sheffield survey reported previously 81% of respondents said that they were easily angered, and 34% reported that they had been violent. It is a common reason for carers to seek professional help. This is not to say that every person with AS is violent, but that violence when it occurs can be particularly problematic, partly because it may not be restrained by empathic responses to other’s fear or pain, and partly because it may appear to be unheralded. The triggers, the warning signs and the context of different kinds of violence are familiar to most people, but this knowledge may not apply to people with AS whose violence may be directed against a vulnerable other person and not the one who triggered it, and it may be temporally remote from its trigger, too.

Some predictors of violence in young people without autism do apply to people with AS, too. A preoccupation with weapons, with violent
videos or violent role models, a lack of social influence in everyday life and rumination and sometimes rehearsing a violent act may all be predictors, although their non-specificity reduces their value in practice. More work needs to be done in predicting those individuals with AS who go on to perpetrate very serious violence, including unlawful killing. Our own anecdotal experience suggests that there is particular danger when a person feels (i) that ‘neurotypicals’ are all of a piece, and that their uncaring treatment of the person with AS justifies retaliation and (ii) that there is nothing to lose. For some people with AS, life imprisonment provides no worse quality of life than the life they have in freedom.

Other forensic problems include stalking, and fetishistically related offending, of which paedophilia often presents the greatest concern. So little research has been on these problems that no general advice is possible except that the outrage that the behaviour causes is often one of the factors that maintains it because it confers a power to have an impact on the person with AS that they find rewarding, however harshly they are treated as a result.

**What contribution do people with AS make to society?**

Most people with AS are still undiagnosed, and it is likely that many of them have escaped professional attention because they are living and working with others. Not everyone with AS needs, or wants, a diagnosis. Some feel that society should make more efforts to include them, but others have found ways to integrate into society.

We might draw two inferences from this. First, services for people with AS need to take their contribution to society into account. Some people with the condition will need life-long social support, but others may need help only during crises, and yet others may never need a specific intervention at all. It is likely that most of this latter group will be people who have abilities of value to others that outweigh their social impairments. They may be adults who remain devoted to elderly parents, while other, non-autistic children will have grown away. They may be people with special talents. People with AS have made original contributions in many fields including the graphic arts and music. Baron-Cohen et al.\(^8\) has suggested that academic engineers and mathematicians include a higher than expected proportion of people with AS. People with AS may have a special interest in these subjects, but they may also have an originality, a single-mindedness and an attention to detail that makes them good academics. Not just good academics, but sometimes geniuses, or so it has been suggested: Wittgenstein, Newton and Einstein have all been retrospectively diagnosed as having AS.
Further information about autism

There are many excellent books about autism, AS and other PDDs, many now written from the different perspectives of the health professional, teacher, employer, spouse, parent, sibling and, increasingly, sufferer. Many of these titles are published by Jessica Kingsley or by the National Autistic Society. Their lists should be consulted for further information.

There are many support groups for parents around the country, and an increasing number of social groups for people with AS. Details can be found from the National Autistic Society. There is a newsletter published by people with AS. Supported employment schemes (‘Prospects Employment Consultancy’) specifically for people with AS have been set up in London and the South-East, Sheffield, Glasgow and Manchester.

There are many specialist schools, some now specializing in AS. There is also an increasing amount of specialist residential provision. Again, the National Autistic Society is a good starting point.

There is a considerable amount of information available on the net. There are discussion groups for people with AS, for students with AS and for counsellors of people with AS. Many people with AS have their own webpages. There is a regular electronic conference about aspects of autism: . The National Autistic Society site, the Autistic Society of America (www.autism-society.org) and the OASIS site (www.udel.edu/bkirby/asperger) are all good jumping off places. The Surrey Autistic Society site contains useful practical information.

Useful medical updates can be found from the CDC webpages.

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References


