

Good practice in the management of autism (including Asperger syndrome) in adults

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Executive summary

- 1 This document, which is to be read in conjunction with other guidance on autism (notably the NICE guidelines; National Institute for Health and Clinical Excellence, 2012), is aimed at psychiatrists working with adults of at least normal intellectual ability.
- 2 Autism is particularly prevalent in the population presenting to adult mental healthcare services, where it may be misdiagnosed or its presence obscured by comorbid psychiatric disorder.
- 3 Anxiety, depression and bipolar disorder are especially associated with autism, but it can be mistaken for, or complicate, a wide range of disturbance.
- 4 Although an increasing number of people are diagnosed in childhood, in many areas, the majority of individuals with autism are likely to be unknown to themselves and to services.
- 5 It is unknown whether there is an increased prevalence among offenders but, when present, autism may alter the nature and management of the individual's offence.
- 6 A psychiatrist might be expected to diagnose straightforward cases of autism and to be alert to indications for a more specialist assessment.
- 7 Although a clear diagnosis is crucial, the process should not stop at simply allocating a label, but should be part of a wider assessment of its purpose and its implications for the individual.
- 8 The management of autism is primarily about the provision of education, training and social support/care for those who have not acquired sufficient skills to function in the everyday world. An individual might expect therefore to draw on resources outside the health service.
- 9 Psychiatry has to deal effectively with the psychiatric disorders that coexist with autism. In this, it must work with others, whether within the health service (specialist autism teams) or external agencies (education and employment) or in the independent sector.
- 10 Local commissioners should ensure that there is a coherent service for people with autism that does not allow vulnerable individuals to be lost in boundary disputes between the variety of mainstream and specialist services, let alone funding agencies.

Purpose of this report

This report is intended to be read in conjunction with the National Institute for Health and Care Excellence (NICE) guidance regarding adults with autism (National Institute for Health and Clinical Excellence, 2012). In line with this, the report uses 'autism' to include all conditions on the autism spectrum, whether childhood autism, autism spectrum disorder, autism spectrum condition, Asperger syndrome, atypical autism or pervasive developmental disorder. This report replaces and updates CR136 (Royal College of Psychiatrists, 2006).

The report focuses on the role of psychiatrists, while recognising that this is only one component of a much wider range of services (Powell, 2002). It is limited to work with adults (adulthood taken here to begin after the 18th birthday), a field of practice in which rigorous evidence is limited. The report takes a broad, pragmatic approach that also draws on clinical expertise and opinion to inform its conclusions.

This guidance is focused on standards of care for adults who do not have a general intellectual disability, people identified by terms such as 'high-functioning autism' and 'Asperger syndrome'. It is their needs and difficulties that this report addresses and it is written primarily for psychiatrists other than those in the specialties of intellectual disability and child and adolescent psychiatry.

The presentation of someone with autism and the resources they require will be influenced by the setting in which they find themselves as well as by the presence of any comorbid disorder. While it may be the latter that leads to the referral to psychiatry, its management will be influenced by the presence of autism.

Concepts and terminology

Autism is one of a range of neurodevelopmental conditions and is defined in ICD-10 and DSM-5

(World Health Organization, 1992; American Psychiatric Association, 2013) by characteristic difficulties in reciprocal social relationships and communication, together with restricted, repetitive or stereotyped behaviour, interests and activities associated with difficulties with flexibility and a consequent preference for predictability and routine. Onset is in early childhood and, although the presenting problems are likely to change and indeed may diminish over time, it is usually lifelong. Asperger syndrome, included in the international diagnostic classifications only in the 1990s, was distinguished by the presence of relatively fluent speech and the absence of a general intellectual disability.

A number of substantial changes have been introduced with DSM-5. First, as research had found little evidence of distinct subtypes, it adopted 'autism spectrum disorder' (ASD) as a single category to include all the other subgroups, including Asperger syndrome (it has redefined those with Asperger disorder as automatically having ASD). However, despite being under scientific notice, the term Asperger syndrome has been adopted by many to describe themselves and is likely to remain in everyday use. Second, the diagnostic criteria have been condensed into two domains:

- *social communication difficulties*, a domain that results from the merger of social and communicative symptoms;
- *restricted and repetitive behaviours*, a domain broadened to include the presence of unusual sensory responses to the environment.

Third, DSM-5 also acknowledges that the child's difficulties may not be recognised until social expectations increase beyond their coping strategies, and this may not be until they start school or even later. Fourth, it is recognised that although (in common with other developmental

disorders) autistic characteristics may diminish and change with age, there is an increased risk of experiencing a range of other, co-occurring developmental and psychiatric disorders. In turn, these adversely affect both the individual's functioning and their eventual outcome. Finally, DSM-5 has created a new separate category 'social (pragmatic) communication disorder' for individuals who have social impairment in the absence of both restricted/repetitive behaviour and anomalous sensory responses. Controversially, this has been categorised as a form of communication disorder, rather than a variant of autism, and its validity and utility have yet to be established.

The categorisation of autism and its diagnostic criteria in ICD-11 are under review, with publication planned for 2015.

There is a great variability in the range and intensity of autism's characteristics. The result is a spectrum of presentation that shades from the florid, through variants (which, although subtle, may still bring social disadvantage), to blend into traits found in the general (neurotypical) population ('neurotypical' is a widely used term to identify individuals who do not have a significant neurodevelopmental disorder). It is a clinical judgement as to whether the individual's characteristics are sufficient to cross the required diagnostic threshold (DSM requires a significant impairment in current functioning). On which side of this boundary an individual falls will depend not only on their innate characteristics, but

also on their current circumstances and mental state for, as with all psychological conditions, distress may well amplify symptoms and result in not just a deterioration in everyday functioning but a more catastrophic decompensation.

Such variability has meant the development of several different ways in which autism is perceived, for example:

- autism as a *disorder*, with the possibility that, one day, it might be treatable; its inherent difficulties mean that individuals are less able to cope with the confusion of an ever-changing neurotypical world;
- autism as a *disability*, a condition that requires specialist remedial education and environmental adaptations to help the individual to enjoy as independent a life as possible;
- autism as one component of the range of *neurodiversity*: an innate difference (much as someone might be left-handed, of an unusual skin colour, stature or gender preference or, indeed, part of any minority group) rather than a deficit; the difference is thrown into relief by an alien world attuned to neurotypical normality.

These models are not mutually exclusive and, depending on their circumstances and needs, people draw on whichever model is of most use to them at the time.

Epidemiology

Prevalence

Epidemiological data on the prevalence of autism in adulthood are limited. Most information is derived from groups (such as clinic attenders) that are skewed by selection bias or is extrapolated from childhood studies.

Initially, autism was thought of as a discrete disorder, occurring in only 0.04% of the population, of whom about 80% also had a general intellectual disability, but over the past 30 years, the definition has broadened with some loss of clarity. Changing concepts and diagnostic practice have combined with greater awareness, and the result has been a startling increase in the number of people identified with autism. However, this still does not exceed what might be expected from the current estimate of a population prevalence of at least 1%, of whom nearly half are of average or above average IQ, a figure supported by the following two UK community studies.

- In 9- and 10-year-old children, an urban population study found a prevalence of 1.16%, of whom 45% were of at least normal IQ, 40% had a mild and 15% had a moderate/severe intellectual disability (Baird *et al*, 2006).
- In adults, a case-finding population survey in England found a prevalence of 1% (after excluding those with moderate/severe intellectual disability), of whom startlingly few had been diagnosed previously or were known to services (Brugha *et al*, 2011). This study was supplemented subsequently with a survey of adults who had a moderate/severe intellectual disability to arrive at a similar overall population prevalence of 1.1% (Brugha *et al*, 2012).

Autism's characteristics are usually at their most florid in early childhood and thereafter tend to improve over time, whether as a result of innate maturation, learned compensation or

circumstances that are less demanding. Although the trajectory in later life has yet to be determined (Mukaetova-Ladinska *et al*, 2012), the adult population survey did not find prevalence to change with age (Brugha *et al*, 2012), although milder characteristics might become subclinical, only to emerge in a crisis or an adverse environment (Balfe *et al*, 2011; Fein *et al*, 2013). All the same, those whose traits fall below the diagnostic threshold may well retain a number of disabilities in areas such as perception, cognition, communication and motivation which, although 'hidden', may hinder the individual in leading their independent life.

Although intellectual disability is an important determinant of support needs, normal (or above normal) IQ does not guarantee a favourable outcome. Of those identified in childhood, only 16–50% become fully independent as adults and, here, the higher figure might reflect an unusually supportive community (Engstrom *et al*, 2003; Farley *et al*, 2009; Howlin *et al*, 2013).

An increased prevalence of autism has been reported in groups that are at a socioeconomic disadvantage (Rai *et al*, 2012a) or migrant (Magnusson *et al*, 2012), factors that might contribute to a greater prevalence in an African–Caribbean population (Goodman & Richards, 1995; Dyches *et al*, 2004; Keen *et al*, 2010) in the absence of any evidence of global geographical variation (Elsabbagh *et al*, 2012). This is complicated by a US study which suggests that ethnicity may not only delay engagement in the diagnostic process but also prolong the process itself (Mandell *et al*, 2007).

Comorbid disorders

Autism is associated with a number of comorbid disorders that can affect the individual's presentation and management, colouring factors such as their communication, flexibility

of thought and even their ability to engage in the clinical process. The overall effect can be to overshadow the underlying autism, which can then go unnoticed. Although it is unclear how far this association with comorbid disorder applies in the wider community, early results from an adult population survey suggest an increased risk of suicidal thoughts and acts (V. Jordanova, personal communication, 2014).

Although, at a little over 1%, autism is relatively uncommon in the general population, it is much more likely to be encountered in psychiatric practice, where one study found it to be present in 3% of patients (Nylander & Gillberg, 2001).

Complicating this, the characteristics of autism may become so pronounced under stress (whether psychological or physical) as to be difficult to distinguish from those of comorbid psychiatric disorder. The result is a person whose symptoms may come from a comorbid disorder, autism or a combination of both.

Comorbid neurodevelopmental conditions

In common with other neurodevelopmental conditions, autism may occur with a variety of specific developmental disabilities, including cognitive impairment in areas ranging from perception to executive function, which, although they come in clusters and are grouped into diagnostic categories, are not specific to a given condition. For example, inattentiveness and distractibility, central to attention-deficit hyperactivity disorder (ADHD), are also seen in autism; compulsive behaviour is a component of Tourette syndrome as well as of obsessive-compulsive disorder; and motor clumsiness, a core feature of developmental coordination disorder, is associated with Asperger syndrome. Limited theory of mind (mind blindness) occurs not just in autism, but also where there has been early sensory impairment and in schizophrenia. The well-defined boundaries of these disorders have blurred to the extent that it throws into question the validity of the initial constellations (Ronald *et al*, 2006). A single categorical label may only caricature an individual with a complex mix of characteristics who should have a broader, more descriptive diagnostic assessment.

Unsurprisingly in view of the overlap of symptoms, autism is associated with other neurodevelopmental disorders. In children, ADHD is present in 30% (as against 4% in the general population), tics in 10% (v. 6%), developmental coordination disorder in 70% (v. 25%) and epilepsy in 5% (v. 1%). There are fewer data for adults, but most neurodevelopmental disorders improve with age, so that, for example, ADHD reduces to about 2.5% (Simon *et al*, 2009) and tics to 0.7% (Schlander *et al*, 2011). However, as yet, we do not know how the presence of autism affects this pattern of change, although there is an indication that epilepsy continues unchecked in 5–15% of those who do not have an intellectual disability (Rai *et al*, 2012b; Tuchman, 2013).

Hearing anomalies are more frequent in autism than in the general population. Again, this finding comes from selected populations (Rosenhall *et al*, 1999) and is complicated by the possibility that the impairment itself may contribute to the autistic symptoms (Hindley, 1997).

Abnormal genotypes have been associated increasingly with autism, not all of the identified syndromes resulting in intellectual disability (e.g. neurofibromatosis, Klinefelter syndrome, fragile-X syndrome and Turner syndrome). They do not occur with sufficient frequency to warrant routine genetic testing unless there is some additional indication (such as intellectual disability or dysmorphism). However, this is a fast changing field and it should be reviewed regularly with the regional genetics centre.

Comorbid psychiatric disorder

Comorbid psychiatric disorder, ranging from emotional and mood disorder through to psychosis, has been reported in 16–35% of adults with autism (Balfe & Tantam, 2010), a prevalence that is consistently higher than in the general, neurotypical population (Brugha *et al*, 2001). Not unexpectedly, it often leads to a deterioration in overall function and a poor outcome in the long term (Hutton *et al*, 2008).

For many, autism in adolescence is characterised by victimisation and bullying (Balfe & Tantam, 2010), with poor social skills contributing to (and resulting from) adverse social events and experiences. For some, there are difficulties in establishing social

and sexual identity, and autism is over-represented among individuals with eating disorder (Berkman *et al*, 2007) and gender identity difficulties (Ray *et al*, 2004; de Vries *et al*, 2010).

An association has been reported with a number of specific disorders.

- *Anxiety* occurs in 7–22% of those with identified autism, varying from specific phobia to social phobia to generalised anxiety (Gillott & Standen, 2007; Davis *et al*, 2008). While a mild anxiety may amplify the characteristics of autism, its more acute and intense form may lead the individual to panic, freeze or develop a psychotic adjustment reaction.
- *Depression* occurs in 15–42% of individuals with autism; accompanied by mania it occurs in 9% (Munesue *et al*, 2008).
- It can be difficult to define the point at which the unusual rigidity and routines of autism become the ego-dystonic symptoms of *obsessive–compulsive disorder*: indeed, the clinical presentation may include features of both (Cath *et al*, 2008; Ivarsson & Melin, 2008).
- The relationship with *psychosis* is more difficult to determine (Palmen & van Engeland, 2012) but, whether or not autism might predispose to schizophrenia, it is not protective. Its phenomenology overlaps with that of the schizophrenia spectrum (King & Lord, 2011) and this, coupled with autism's communication difficulties, means that some care and a detailed developmental history is needed to pick the two apart.
- *Catatonia* is an ill-defined syndrome that can occur in schizophrenia but also with other disorders, and its characteristics run through neuropsychiatry (Cavanna *et al*, 2008). These characteristics, such as stereotypies, complex mannerisms, difficulty in initiating voluntary actions, echolalia, unusual slowness, passivity and freezing, are not unusual in autism. Particularly striking is ambitendence, in which the person, unable to complete an intended action, withdraws and tries again so that a straightforward action becomes a hesitant stutter. Such characteristics occasionally become so severe as to interfere with the person's everyday functioning (Wing & Shah,

2000; Dhossche *et al*, 2009; Rosebush & Mazurek, 2010). However, they do not mean that the person is psychotic.

Autism does not exclude the presence of a coexistent personality disorder, although their similarities in presentation may cause autism to be mistaken for borderline (Smith & Hobson, 2013) or other personality disorders. This is particularly likely where there is an undue reliance on standard instruments such as the Hare Psychopathy Checklist – Revised (PCL-R; Hare, 2003), the Minnesota Multiphasic Personality Inventory (MMPI; Ozonoff *et al*, 2005) and the Yale–Brown Obsessive Compulsive Scale (YBOCS; Goodman *et al*, 1989).

Finally, the psychiatrist must be alert to the increased risk of psychiatric disorder in the immediate family of someone with autism, an association that is more than simply the consequence of living with someone with autism (Piven & Palmer, 1999; Daniels *et al*, 2008). However, whatever the aetiology, the presence of psychiatric disorder in those closely involved will inevitably affect the person with autism and their management.

The criminal justice system

Although the majority of individuals with autism are law-abiding (and even rule-bound), there is a debate as to how far this might be offset by the few whose characteristics predispose them to entanglement with the law (for examples, see p. 21) (Barry-Walsh & Mullen, 2004). In the absence of systematic community studies, our present knowledge and understanding comes from the slowly growing number of clinical studies, reports in the professional literature and a small number of cases that have received extensive media coverage (Mouridsen, 2012). Besides publication and selection bias, there is an element of chance in the process that identifies an individual as an offender. Factors such as being caught, charged and convicted will be influenced not only by a person's underlying neurodevelopmental disorder, but also by the extent to which this is recognised by others, as well as the attitudes, support, supervision and tolerance of all those involved.

Two studies carried out in UK high secure psychiatric hospitals have indicated that there might be an increased prevalence of autism (Scragg & Shah, 1994; Hare *et al*, 2000), but the specialist nature of these settings prohibits

extrapolation to other hospitals or prisons. A more recent study in Scottish prisons highlights the difficulty in identifying individuals with autism, let alone estimating its prevalence (Robinson *et al*, 2012).

Policy

Wider recognition of the occurrence of autism in adults without an intellectual disability has led to a shift in the perception of autism and a public demand for better resources, greater awareness and a higher level of professional expertise. It has become clear that, rather than having an isolated disorder, an individual with autism will have a personal profile that includes a mix of neuro-developmental disabilities and strengths which, in turn, affects their development over time. In addition, there is the likelihood of developing a comorbid psychiatric disorder, with its particular effect on the individual's presentation and management plan.

Disability should not bar anyone from access to any clinical services, including mental healthcare, but, for some, these will need to be buttressed by more specialist services. For people with mild intellectual disability and mental health problems, the Royal College of Psychiatrists (2012) places an emphasis on a more inclusive mainstream mental health service with well-coordinated support by specialist intellectual (learning) disability services. All services, including specialist services (e.g. psychotherapy, forensic and old age psychiatry), must consider how they will meet the needs of patients with autism.

Particularly if it is compounded by coexisting disorder, autism can reduce an individual's functional ability to a level where they require long-term support. In this situation, adults can find themselves in a limbo between the various psychiatric specialties: too able to be included within the contracted services for intellectual disability, but with developmental disabilities and support needs unfamiliar to the various mental health specialties, many of which are more used to dealing with recovery models of episodic care.

England

The Autism Act 2009 was followed by three documents (Department of Health, 2010a,b, 2014) that put a legal obligation on local authorities and all NHS organisations to anticipate the needs of adults with autism and to plan for the development of appropriate services in each local area, such services to be overseen by a local ASD strategy group. Local autism commissioning plans are to be part of local joint strategic needs assessments (JSNAs) and to include a pathway to diagnosis, appropriate treatment, support, occupation, housing and leisure services as well as training for all staff working for health, social care, education and independent providers. Progress has been subject to formal review over the past year. Commissioning guidance has been issued by NICE (National Institute for Health and Care Excellence, 2014a) and further advice is to follow from the Joint Commissioning Panel for Mental Health (2014).

A NICE guideline on the diagnosis and management of autism in adults was published in 2012 (National Institute for Health and Clinical Excellence, 2012), supplemented by service quality standards (National Institute for Health and Care Excellence, 2014b).

In July 2012, the Care Bill was released as a White Paper (Secretary of State for Health, 2012). It is intended to reform the law relating to care and support for adults and their carers, replacing all current legislation on social care with one single statute to give an improved system, consistent across England and easier to understand and access.

Wales

The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales was published in 2008

(Welsh Assembly Government, 2008), the first of the specific autism strategies in the UK. A 10-year programme with ring-fenced funding, it set out key actions, which include the establishment of local stakeholder groups to help shape local provision and the appointment of local autism leads. It set up a 'task and finish' group to look at the specific needs of adults with autism and proposed a public consultation prior to the plan's revision.

An All Wales Adults Diagnostic Network was established to provide diagnosis and support for adults with autism irrespective of their cognitive ability.

The Social Services and Well-being (Wales) Act 2014 gives a coherent legal framework for social services with a focus on provision that comes from the needs of individuals and their carers, is flexible and also might prevent the development of additional needs.

Scotland

The needs of adults with autism were identified in *The Same as You?* (Scottish Executive, 2000), which put an emphasis on early diagnosis and the adaptation and development of suitable services, whether specialist or mainstream. Prompted by a needs assessment report (Public Health Institute of Scotland, 2001), recommendations embraced all individuals with autism, irrespective of ability (Scottish Executive, 2003), and were followed by a review of people detained in secure settings (Scottish Executive, 2004). The upshot was the Scottish Strategy for Autism, developed jointly by the Scottish Government and the Convention of Scottish Local Authorities (COSLA) (Scottish Government, 2011). Its recommendations included best value in service provision, cross-agency working, collaboration and involvement, diagnosis,

intervention and support, wider opportunities and access to work. This has led to a wide range of activities that include a pilot of One Stop Shops (p. 24), an examination of the cost-effectiveness of certain interventions and the mapping of services and need across Scotland (Jones & MacKay, 2013). More specifically, a working group, the Autism Achieve Alliance, has been commissioned to investigate and to make specific recommendations to improve the diagnostic process.

Northern Ireland

The Autism Act (Northern Ireland) 2011 had two main aims. The first was to amend the Disability Discrimination Act 1995, broadening the assessment criteria to include a person's social interaction. The second was the development of a cross-departmental Autism Strategy (2013–2020) and Action Plan (2013–2016). Published in January 2014, this was led by the Department of Health, Social Services and Public Safety (DHSSPS), which has set up a pilot multi-agency autism advice service.

The Channel Islands

In Jersey, there is an Autistic Spectrum Partnership Board, which comes under the Joint Secretariat for People with Special Needs and their Families. The Board is responsible for the development and delivery of services and is developing a specialist autism centre and team.

The Isle of Man

There is no specific provision for autism in the legislation.

Recognition, diagnosis and assessment

Recognition

The psychiatrist first has to think of the possibility of autism; only then can they select the individuals who warrant a more detailed diagnostic assessment. It can be more difficult to diagnose autism in adults and older people than in children because of the effects of maturation and compensatory learning and adaptation. Many people have traits that appear autistic and, as stated earlier, it is a clinical judgement whether these traits are sufficient in both number and intensity to impair everyday functioning and warrant a diagnosis of autism. The very generic characteristics set out in the NICE guidelines (National Institute for Health and Clinical Excellence, 2012) are appropriate to the wider population of primary care. Given the prevalence and complexity of psychiatric symptoms in patients presenting to mental health services, the following more specific indicators may alert the clinician.

- *Difficulties in social interaction* – which might include social awkwardness, restricted social responsiveness and a limited ability to take part in meaningful to-and-fro conversation. A reduced intuitive understanding of how others might think or feel may emerge as a difficulty in understanding the nuances of social situations, a proneness to social blunders or an unthinking unconcern for others. In the longer term, there may be difficulty in making and maintaining reciprocal friendships (as distinct from the ability to strike up (but not retain) new acquaintances). Wherever possible, it is essential that the clinician gets accurate accounts of relationships in different settings (e.g. at work and at home), particularly where they might be more demanding for that individual.
- *Limited non-verbal communication* can manifest in an unusual use of gaze, facial expression and gesture: elements which may be poorly integrated with each other as well as with what is being said. This differs from the persistent avoidance of gaze that is seen in shyness or depression. Speech, which may have a pedantic correctness, may lack vivacity and sound unusually even in pitch and pace. An inability to appreciate the non-verbal component of speech not only leaves the individual struggling to understand what is being said, but may lead to serious misunderstanding. A frequent and natural pitfall is the assumption that, should someone appear fluent, demonstrative and well able to express themselves, their comprehension matches their expression. The clinician must guard against this, regularly checking that they have been understood.
- *Interests and activities* that are unusual in their intensity, content or the amount of time they absorb, particularly when they lack a social aspect. Such an enthusiasm can lead someone to develop an expertise in a narrow, specialist field that is unusual in comparison with their other abilities.
- *Unusual sensory responses*: the person may be unusually aware of a variety of sensory experiences and stimuli – whether drawn to or repelled by them. These can be as diverse as certain sounds, flickering lights, repetitive movement, clothing texture or minor anomalies such as cracks in walls, the pattern of a fabric or the hum of a neon strip light. The result is that the individual can seem to be very distracted, day-dreaming or even hallucinating, being preoccupied with

experiences that others cannot appreciate. (This characteristic can be seen across a number of neurodevelopmental disabilities.)

- *An inflexibility* that results in a person who becomes very set in their ways, with fixed routines and an aversion to anything new. This differs from obsessive–compulsive behaviour in that the individual does not feel the behaviour to be alien and has little desire to change (particularly if they are doing something they enjoy).
- *Something unusual about a psychiatric disorder*, such as an atypical presentation or a failure to respond to treatment.

While a normal (neurotypical) premorbid personality would make a diagnosis of autism in adulthood unlikely, as mentioned earlier, an individual's difficulties may remain unnoticed if they are mild and if the person has been in supportive circumstances (e.g. a well-organised, 'structured' primary school).

Autism may mask or mimic a wide range of psychiatric symptoms and the mental state examination should confirm that the symptoms are what they seem. For example, difficulty in describing their internal states may make it impossible for someone with autism to describe their thoughts or feelings, leaving them unable to identify anxiety or depression. An impression of hallucinating may result simply from the person's detachment coupled with the clinician's failure to understand the person's distraction by an idea or their sudden and intense attention to something they have noticed. An individual's report that they have many friends may be undermined by the discovery that they are unaware of what is meant by friendship. The clinician needs to find a balance between overlooking autism and seeing it in everything.

The nature of diagnosis and assessment

Diagnosis

Clinical diagnosis is the allocation of a series of categorical, descriptive labels that summarise

whether an individual's characteristics meet the diagnostic criteria, agreed by consensus and set out in such systems as ICD-10 (World Health Organization, 1992) and DSM-5 (American Psychiatric Association, 2013). It is a classificatory, two-part process that relies on clinical evaluation and judgement to determine, first, whether the key characteristics are present and, second, whether their intensity is such as to cause a disability or disorder (rather than simply being personality traits). However, the criteria reflect evolving concepts, and alternatives have emerged, notably for Asperger syndrome (Gillberg, 1998). Diagnosis may also take the form of a formulation, a summary description of the individual's predicament and the contributory circumstances.

Assessment

Although diagnosis is a crucial step, it is only one component of the wider multidisciplinary (and potentially multi-agency) exercise advocated by NICE as the initial step in making a plan that aims to help the individual to lead as full a life as possible with the appropriate help of carers, professionals and various agencies (National Institute for Health and Clinical Excellence, 2012). Tailored to the strengths, skills, needs and impairments of the individual, the range of assessments might include the following.

- *Cognitive ability* – measured by various forms of formal intellectual test, this might also identify discrepancies between verbal and performance abilities as well as the variety of specific disabilities that can accompany any neurodevelopmental disorder (such as difficulty in recognising faces or ages, appreciating time, or understanding spoken as against written language).
- *Functional ability* – acknowledging the extent to which there may be difficulties in a wide variety of areas, such as everyday living skills, social relationships, communication (receptive and expressive), imagination, occupational and executive function, as well as identifying areas of skill and talent that might be developed. All of these will govern the extent to which individuals can look after themselves, manage independently, take up

education, employment or leisure activities, develop relationships and cope with the social demands of other people.

- *Coexistent neurodevelopmental disabilities* – notably these include ADHD, tics, sensory anomalies and coordination disorder as well as epilepsy.
- *Coexistent psychiatric disorder* – these include anxiety, depression, obsessive–compulsive disorder and psychosis.
- *Mental capacity* – the criteria for determining mental capacity and their underlying principles are well established, but the sometimes subtle characteristics of an individual with autism need to be reviewed carefully against these criteria.
- *Other elements* – these include the risk of coming to harm or of offending.
- *Medical problems* – there are those that might be associated with autism (epilepsy, atopies, gastrointestinal problems or infections) as well as any other disorder that might have been overshadowed by the presence of autism (such as obesity, cancer and dementia).

The purpose of diagnosis

A diagnosis can help to explain to others the need for support and the form it should take, but on its own is insufficient. A diagnostic formulation can inform care planning and may lead to more appropriate support, accommodation, education and occupation, with the overall aim of a more successful integration into the wider community. It may be the springboard to relevant information, specialist support groups and resources (including financial benefits), could avert a crisis and may allow diversion from hospital, the court or prison. In short, diagnosis has many functions and its purpose will colour the assessment as well as the clinician's threshold, depending on whether it is for clinical, research or administrative purposes.

- *Research* – where the criteria will depend on the nature of the study. An individual may be excluded because their profile does not meet the study's inclusion criteria, or there is limited

information or simply doubt. Exclusion does not necessarily mean that they do not have autism.

- *Clinical* – where the diagnosis is simply a summary of the individual's needs and difficulties.
- *Administrative* – here the diagnosis may facilitate entry to services, resources or a specific outcome or disposal, particularly where these are determined by label rather than need.

There is no definitive laboratory test for autism. Diagnosis is a clinical judgement that may become clearer over time as more information is gathered and circumstances change. A categorical decision may be needed, but management is anything but categorical as it has to be tailored to the individual and their place on a wide spectrum of potential disability and comorbid disorder. At one extreme are individuals who, reassured to learn that, although different, they are not disturbed, can move on, better able to ask for acknowledgement or support when it is needed. At the other end are those who need full-time support and care. In between are those who might go onto a pathway of stepped care that, at different times, may range from 'watch and wait' through to major multidisciplinary/multi-agency involvement.

The process of diagnosis

People come to diagnosis by various routes. Some, drawing on a variety of sources, including books, self-rating scales and the internet, will have found that autism might be a way of understanding themselves and are seeking to confirm or refute this. Others may have a close relative with autism and have come to recognise similar traits in themselves. They (or their family/carers) may know a great deal about autism and have substantial expectations of what might happen once the diagnosis is made. Then there will be some who, diagnosed in childhood, wish to have the diagnosis reviewed and perhaps removed.

It cannot be assumed that most people will have been diagnosed by children's services. Although

autism is becoming more readily recognised and managed from early childhood, there are some for whom it takes the developmental changes of adolescence, the difficulties of peer relationships or the more complex structure of secondary schooling to bring out their characteristics sufficiently for the syndrome to be recognised. Even then, depending on the sensitivity to autism of their local services, many will reach adulthood undiagnosed, their autism coming to light only with adversity. This may take a variety of forms, including the environmental pressures of work, redundancy/retirement, a change in social or marital relationships, entanglement with the law or the onset of comorbid psychiatric disorder. For others, the significance of a childhood diagnosis may have been lost as they move between services.

It is essential to obtain the individual's consent to the diagnostic process (if they have capacity), particularly if there is any concern about the individual's level of social understanding or independence. Their wishes may be overlooked by family and/or carers, who may not appreciate that the individual has capacity to withhold consent, whether to diagnosis or to the sharing of information (Royal College of Psychiatrists, 2010). For example, an individual might see the diagnosis as stigmatising or as hindering their career. At any rate, the purpose and potential benefit of diagnosis must be explored early in the process.

In making a diagnosis in adulthood, the psychiatrist should:

- speak with an informant
- take a neurodevelopmental history
- consider obtaining early health records.

The psychiatrist should remember that individual characteristics are not pathognomonic of autism: difficulties with social understanding and non-verbal communication run through psychiatry, as do sensory anomalies and obsessive symptoms.

In the end, much will depend on the extent of the clinician's experience, their rigour in applying standard criteria and their ability to recognise alternative diagnoses. Time is also a factor and, although a diagnostic process that focuses

only on the current features may be relatively brief (particularly if it complements a psychiatric interview), it is important to remember that the conclusions can have far-reaching consequences. Subtle or complex cases usually require more time, such that a definitive interview, sufficient to refute as well as confirm the diagnosis, may take several hours. It is not to be undertaken lightly or without sufficient resources.

The diagnostic process must take account of the potential for characteristics to be missed or misinterpreted when they present in someone from another culture or where a different language is spoken. Allowance must be made for the way the culture may interpret the characteristics, potentially placing a different emphasis on social as compared with communicative difficulties (Dyches *et al*, 2004; Mandell & Novak, 2005). This applies not just to those from an unfamiliar ethnic group but also where there are other disabilities, such as hearing or visual impairment or intellectual disability.

The potential for confusion with a comorbid disorder means that the clinician requires:

- a familiarity with autism in its various manifestations and circumstances
- a familiarity with a wide range of psychiatric disorders, both to recognise comorbid conditions and to avoid the misdiagnosis of other conditions as autism
- a developmental perspective in taking the history.

The interview with the individual should be adapted to the underlying characteristics of autism. Techniques include the following.

- Reducing anxiety (here, the advice of friends and carers may be helpful to the clinician).
- Using straightforward, unambiguous, simple language and short sentences and avoiding constructs that might be misinterpreted, such as irony and metaphor. The individual may not notice non-verbal elements, such as gesture, facial expression and tone of voice, so that statements are taken at face value. In some, a rigid style of thinking ('black and white thinking') also encourages a tendency to take what is said literally. A suspicion

of misinterpretation should be reviewed immediately.

- Allowing the person sufficient thinking time to process what has been said. Verbal fluency may give a misleading impression of comprehension. Should the clinician's response be too much or too fast, it may overload the individual's auditory processing so that they are unable to grasp the meaning even though they may be able to echo what has been said – individuals often use echo in an attempt to understand what is said, and this can give a false impression of comprehension.
- Using diagrams and visual text to help comprehension and summarising the main points of an interview in a confirmatory letter.
- Giving a limited number of choices at a time, each with a clear effect.
- Encouraging the presence of a friend or advocate who can help the individual to understand and to digest the content of the interview afterwards.
- Ensuring that the environment is distraction-free, calm and comfortable for that individual. It is helpful to check in advance whether they have any specific sensory difficulties.
- Keeping interviews to a comfortable length; the clinician should be guided in this by the individual.

Diagnostic instruments

The variety of instruments available, ranging from screening questionnaires to interview frameworks

to structured interview schedules, reflects their different purposes: those of more immediate relevance to the general psychiatrist are listed in the Appendix (pp. 28–32). Such instruments help clinicians collect the appropriate information, which can be matched systematically against agreed criteria. Thus, their format provides a useful framework that can support and organise the clinician's thoughts. Although criteria evolve continually, they do hold clinicians to a consistent threshold at the time, and the underlying construct may be refined by an algorithm. Such algorithms serve to operationalise diagnostic categories and give a better picture of their dimensions, but they also bring a misleading mechanical simplicity to clinical cases, particularly where there is an overlay of comorbid disorder. In the end, diagnosis is a clinical judgement.

A number of questionnaires have been proposed to help in the selection of individuals for further assessment, but their effectiveness in primary care is unproven. However, two measures, the Adult Autism Spectrum Quotient (AQ) (the full, 50-item version) and the Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R), have been shown to be valid in psychiatric populations (T. Brugha, personal communication, 2014). The College has developed a Diagnostic Interview Guide for the Assessment of Adults with Autism Spectrum Disorder (ASD) to be used in conjunction with the standard psychiatric interview and provides training in its use. The guide and a related training resource can be downloaded from the College website (www.rcpsych.ac.uk/traininpsychiatry/conferencetraining/courses/dirinfo.aspx).

Management

The management of autism itself is primarily about the provision of the education, training and social support/care for those who have not acquired sufficient skills in self-care and independent living to function in the everyday world (Balfe & Tantam, 2010). Such functional difficulties, which relate to autism rather than being the consequence of intellectual disability, may be helped by a variety of non-clinical resources that lie outside the health service. For example:

- peer group support through the internet and voluntary groups such as the National Autistic Society (NAS)
- support and residential services: these include a range of options, from registered care through to independent supported living (although claims of specialism/familiarity with autism should not be taken at face value)
- educational services, including both higher and further education. Increasingly, universities, recognising the need for social as well as academic support, have introduced disability coordinators. Further education colleges have the potential to include more specific areas, such as:
 - social skills, including tuition in social and sexual rules
 - emotion management, covering areas such as emotional literacy (the ability to identify and describe feelings), relaxation training, stress reduction and anger management, with as much emphasis on averting as on dealing with arousal
 - independent living skills in all the areas necessary to an independent life – e.g. shopping, budgeting, housekeeping, laundry and personal hygiene
 - preparation for work (how to apply for a job, interview skills)
 - accessing leisure activities
- occupational support – disability employment advisors (based in Jobcentres) are becoming more familiar with autism and a number of independent agencies have established services to support individuals in work settings (e.g. Prospects, a service established in several cities by the NAS).

Unfortunately, resources are patchy and individuals remain very dependent on families. It is essential that there is an understanding of their circumstances and relationships.

Psychiatric management

Although there is no evidence of any effective psychiatric treatment for the core impairments of autism, the presenting difficulties will be diminished by any approach that reduces the individual's anxiety or increases their comfort and sense of well-being. This may come from improved communication and social understanding, a change to the environment, the relief of physical malaise (including the better management of epilepsy and medication) and the treatment of comorbid psychiatric disorder.

Many interventions are promoted for different aspects of autism, regardless of evidence of their limited effectiveness or, in some cases, their harm. Research Autism provides a regularly updated resource that summarises treatments, their efficacy and any evidential underpinning (www.researchautism.net/autism-interventions/alphabetic-list-interventions).

A tangible treatment can have a powerful placebo effect both directly on the individual and indirectly through its effect on the attitude and behaviour of the family and carers (Sandler & Bodfish, 2000; Sandler, 2005).

Medication

Although there is little research-based evidence for the use of medication for autism in adults, there is rather more for its use in children, as well as for adults with intellectual disability (many of whom will also have autism), and NICE drew on all three sources in reviewing this area (National Institute for Health and Clinical Excellence, 2012). However, where appropriate, medication is only one component of a multimodal approach that might include psychological therapies, education and environmental change, so it should not be used in isolation. There is the aspiration, sometimes realised, that it may facilitate a change that is sufficiently sustained for the medication then to be relinquished. It appears that autism might be a marker for an unpredictable response to psychotropic drugs, with increased and decreased sensitivity in different individuals, as well as more frequent and unusual adverse effects. Drugs should be introduced at a low dose and increased cautiously, with careful monitoring.

There are two particular circumstances that require medication:

- *Psychosis*: emotional stress occasionally leads to symptoms that are difficult to distinguish from those of psychosis. Early treatment of the latter with antipsychotics is so important to the prognosis that it cannot be delayed by diagnostic doubts. At the same time it must be recognised that, while early weaning should be part of the strategy, it can be difficult to disentangle the characteristics of autism from those of the psychosis once an individual has been established on antipsychotics.
- *Epilepsy*: the association of autism with epilepsy (Besag, 2009) has led to trials of various forms of anti-epileptic treatment to improve the characteristics of autism. The results are equivocal in the absence of clear evidence of seizures (Tuchman *et al*, 2010). The arguments expressed in the debate on the use of surgery for ill-defined seizure activity (Palac *et al*, 2002) also apply to the use of anti-epileptic drugs and, in the end, their use should not be influenced by the presence of autism.

Psychological treatments

People with autism may have emotional problems (bullying or loneliness being prominent) and, although these are no different from those of the general population, they are more likely to be provoked by social exclusion and hostility.

Cognitive-behavioural therapy has been reviewed by NICE (National Institute for Health and Clinical Excellence, 2012), but less attention has been given to other types of psychotherapy and counselling, presumably because of the lack of systematic trials of these interventions with people with autism. The lack of evidence, however, is not necessarily evidence of ineffectiveness. At present, best practice would indicate that individuals with autism should have access (albeit with reasonable adjustments) to the types of treatment for anxiety and depression that are recognised as an integral part of mental healthcare for the wider (neurotypical) population. Clinical experience has been that humanistic, especially person-centred, approaches are effective and may even be more appropriate than the dominant cognitive-behavioural model.

The NHS Programme for Improving Access to Psychological Therapies (IAPT) recognises that the provision of therapy should be culturally appropriate and should take account of disability – a category that includes autism. Therapists need to allow for the possible variations in cognitive style, communication, narrative and value system that might come with autism. This may require some adjustments, for example:

- the constraints on an interview listed earlier; these include care in the use of idioms, metaphors and figurative speech, as well as less reliance on non-verbal communication
- less reliance on the patient's autobiographical memory
- not assuming that a patient with autism lacks emotional language, but not relying on the individual remembering the emotional content of previous sessions or being able to put a name to emotions, whether their own or those of others
- focusing on practical matters and problems rather than mentalistic concepts

- an awareness that people with autism may report their inner experience in unusual ways that should not be dismissed or accepted simply as psychotic phenomena
- a readiness to explore the values of the patient and to work within them, even if they are idiosyncratic
- a preparedness to give advice or information.

The families of many people with autism have come to act, whether as their advocates or their next friends, in many settings, with the result that the boundaries of confidentiality are sometimes unclear. The therapist therefore must be prepared to work out with their patients how best they might work with, consult and advocate to these other people with the patient's consent. Although this work should respect the patient's confidentiality, it must also take account of the destructive effect of some secrets.

The relief of anxiety or depression can improve cognitive performance and may reduce the severity of some of the characteristics of autism, notably restricted and repetitive behaviour. However, the evidence that psychological techniques can modify core impairments in non-verbal communication is weak. If an individual with autism requests help with some specific element of social performance, such as what to do in a defined situation or how to interpret specified behaviour patterns in other people, a variety of methods can be used (including social stories, empathy training, role-play and drama therapy) to give guidance and the opportunity to rehearse the application of that guidance in naturalistic settings.

Therapists should also be aware of the potential negative effects of therapy that, besides increasing the emotional demand on the patient, may encourage ruminations about past unfairness or injustice that cannot be rectified.

Legal aspects of psychiatry

As experts, psychiatrists provide information, often to courts, that would not otherwise be known to the legal system. If this is to be given due weight and considered credible, whether in the form of written reports or verbal evidence, then the psychiatrist must be aware of the following.

- It is essential that the opinion is truly independent and not biased by the source of referral.
- It must be clear what is fact and what is opinion: a statement such as 'this individual will be unable to cope with imprisonment' should be based on sound and explicit reasons rather than speculative generalisations. For example, although someone detained (whether in prison or hospital) might find the conditions of an open prison/ward very stressful, they might be relatively comfortable within the structure and supervision of a secure placement.
- Recommended treatments must be available and feasible. This means giving the court specific advice as to where they might seek a suggested regime and, if necessary, confirming its availability with potential providers. Courts will often be willing to defer a decision on sentencing while recommended options are explored, particularly with the health and social care agencies responsible for their implementation.
- Difficulties with comprehension (ranging from a tendency to interpret language literally to problems with auditory processing): it is important to remember that these may be masked by superficially 'mature' speech.
- Difficulties with attention and concentration: these can hinder the understanding of information, particularly if they are made worse by physical discomfort, sensory distraction or anxiety.
- Rigid perceptions of how the world works (or should work) or a rigid misunderstanding of the cause and consequence of particular events: a strong and fixed belief can bias an individual, so that it becomes difficult for them to judge the authority and motivation of information and informants; examples are the belief that publication on the internet means that something must be true or that anything said by certain authorities (police or politicians) is false.
- Problems coping with change: these may result in an overriding aversion to anything new, making it difficult for the individual to weigh up information and judge what is relevant.
- A reluctance to come to a decision: this difficulty may be a consequence of the autism itself (e.g. difficulty coping with too many choices or hypothetical choices) or may result from a comorbid condition such as anxiety or depression (Luke *et al*, 2012).

Mental capacity and consent

There are a number of forms of disability associated with autism that may complicate the assessment of mental capacity and thereby the validity of an individual's consent to treatment. These include the following.

Offending behaviour

Most individuals with autism respect order, are keen to avoid trouble and do not offend. However, there are a number of factors that may offset

this law-abiding respect for rules and result in a vulnerable individual who is predisposed to getting into trouble. These include the following.

- A naive misinterpretation of social relationships may leave an individual open to being drawn into illicit relationships as well as to intimidation and exploitation. Limited emotional knowledge can hinder the development of a mature understanding of adult situations and relationships so that, for example, feelings of social attraction or friendship are misinterpreted as the stronger emotion of love.
- A misinterpretation of rules can result in a failure to appreciate social behaviour. For example, someone who does not understand the point at which 'no' means 'no' may find themselves unwittingly embroiled in offences such as 'date rape' and stalking. Similarly, television and video scenarios can undermine the individual's appreciation of the seriousness of an offence, leading them to copy the behaviour with little understanding that it should not be translated into real life.
- Difficulty in reading social signals and cues: a specific difficulty here is an inability to gauge the age of others, which leaves the individual open to inadvertently making a sexual approach to somebody under age. The problem is compounded for those whose social ineptness has led them to become part of a younger peer group.
- An unusual passivity that leaves the individual open to being influenced, exploited or radicalised by others.
- Impulsivity, occasionally violent, that may be a component of comorbid ADHD, a state of anxiety turning into panic or a confusing blend of both. The result can be an emotional response that is out of proportion to the situation (e.g. a 'meltdown') that others then misinterpret as threatening.
- A limited awareness of the outcome of their actions, their seriousness or their impact on others, which allows the individual to embark on a course of behaviour irrespective of its consequences. For example, a minor assault might become disproportionately intense

and damaging, or what started as limited fire-setting may result in the destruction of a building. Not infrequently there is a lack of insight and a denial of responsibility (blame being ascribed to someone else), with an inability to see their inappropriate behaviour as others see it.

- Overriding preoccupations, which can lead to offences such as stalking or compulsive theft. Here, admonition may increase anxiety and result in ruminative thinking about the unthinkable that increases the likelihood of the behaviour.
- Misjudging the nature of the interview may encourage an incautious frankness. Private fantasies, while no more lurid than those of many in the wider population, may be startling in their clinical detachment and obsessional quality, and the individual's lack of insight can lead to socially inappropriate disclosure.
- A failure to appreciate any need to change (or finding change inordinately difficult) that leaves the individual stuck in a risky pattern of behaviour – a problem that may be made worse by comorbid dysphoria, anxiety or any other mental state that reduces flexible thinking.

Such factors, where they occur, may affect the individual's capacity to make valid decisions and limit their level of culpability, so they need to be taken into account by those deciding whether to prosecute as well as in sentencing and disposal.

The ability to bear witness

Autism may (but does not necessarily) affect the ability to give an accurate account of an event (i.e. to be a reliable witness) (Maras & Bowler 2012). The following potential factors should be considered in assessing this.

- An unusual perception of the significance of events, whether as observer or performer, that increases the individual's risk of misinterpreting what they have seen or heard.
- Difficulty with the dimension of time: although the sequence of events may be recalled

correctly, the perception of the relative periods of intervening time may be distorted, blurring the distinctions between events of the previous day, week or year.

- Difficulty in distinguishing reality from observed fiction may extend to a confusion between their own actions and those of others.
- Difficulty with the normal structure of official interviews, whether in the police station or the witness box: the unfamiliar and formal surroundings and circumstances are likely to increase any innate disability in communication, both verbal and non-verbal. A person with autism may find it difficult to understand the interviewer, particularly if questions are complex, indirect or use metaphors or colloquialisms. The interviewer can be misled by responses given with an inappropriate or limited vocal tone or facial expression (particularly smiling or laughter, which are not unusual as reflex responses to anxiety). Delays in processing speech, selective mutism or simple stage-fright are easily misinterpreted as wilful.
- An interview can be distorted by an individual's misinterpretation of rules and relationships, with undue compliance complicated by a rigid tendency to adhere to (and believe in) a story once it is in their head.

Throughout, there is the risk that a person with autism may not be recognised as a vulnerable adult. A defendant may not be adequately protected by the criteria for fitness to plead (established in *R v Pritchard*, 1836), which emphasise the cognitive abilities of a defendant. A good intellectual awareness of right and wrong, and of the nature of the court and its proceedings, may be insufficient when legal issues become complex (Barry-Walsh & Mullen, 2004; Freckelton, 2012). Defendants may be compromised further by an inability to present themselves effectively, something that has become more important with the removal of the right to silence in England and Wales (Gray *et al*, 2001).

It does not follow that these difficulties are invariably present in autism but simply that, where relevant, they should be considered and investigated as part of the assessment. Once recognised, many of them can be minimised by adjusting interviewing

styles to allow for linguistic and intellectual limitations, for example by using visual materials (such as text and diagrams) to support what is being said, allowing sufficient time for the person to understand what is happening and to express themselves, and checking that a point has been understood before moving on. Preparatory visits to court may help to familiarise the individual with the setting and the proceedings, which might then be made more manageable by arranging for appearances to be at times that are predictable and of a set and limited duration. The judiciary is better informed about the needs of people with autism and more willing to accommodate them in the legal process.

A very clear and helpful guide has been produced for all those involved (National Autistic Society, 2011).

Disposal in the criminal justice system

Disposal will depend on the seriousness of the offence as well as such factors as the risk of further offending. Involvement in terrorism is likely to result in custody even where there is little risk. Some individuals will simply require consistent supervision to prevent a drift back to the circumstances that led to their offence. A requirement for mental health treatment can be added to community treatment orders and suspended sentences, as long as this is agreed by both the patient and the clinician who is to provide the treatment.

However, that the offending behaviour is related to the autism does not, of itself, mean that a treatment will be helpful, although often this can only be judged by seeing the individual's response to it. The courts will not expect a guarantee that treatment will be effective; merely a genuine offer of treatment that may help prevent further offending. These arrangements give an assurance to the court that there will be an attempt to provide treatment for the defendant.

There are some individuals with autism who find comfort in the predictable structure of prison life, particularly in the more secure estate, and may even be reluctant to return to a less

organised life in the community. However, many are vulnerable people who find themselves in conflict with the structure and at an increased risk of suffering serious harm from others; at the least, they are particularly liable to bullying and other forms of victimisation (Scottish Executive, 2004). The result may be increased anxiety or depression and, for some, the degree of stress and consequent arousal may be sufficient to produce a psychotic state.

Where detention is necessary because of the seriousness of the offence, or the degree of disturbance or the risk of reoffending, a hospital order might be considered. It should be only one stage in a longer programme of rehabilitation that eventually leads back to the community, rather than slipping into an indeterminate period of detention in hospital. An alternative is a prison sentence that includes hospital treatment, a strategy that has the advantage of being finite.

Services

Most individuals with autism will require support from a wide variety of local agencies and disciplines. A person-centred approach will need to be adapted to each individual's circumstances, cultures and beliefs and to involve families and carers. Planning for a person with autism requires a broad-based strategy that goes beyond health, education and Social Services to include, for example, occupational, legal, recreational and voluntary services. These need to take account of families from ethnic minorities who may have linguistic barriers, reinforced by mistrust, fear, and misunderstanding, as well as a different understanding of the need for a specialised programme: all of these factors can affect their access to a service, interaction with it and choice of treatments (Dyches *et al*, 2001; Mir *et al*, 2001; O'Hara, 2003). Taking into account the varied ages, abilities and circumstances of individuals with autism, management of the difficulties associated with autism is an extraordinarily wide remit which can involve any of the psychiatric specialties as well as drawing on other disciplines, their services and their expertise. Scotland, in conjunction with its charities, is piloting the One Stop Shop, a community facility that draws on volunteers to provide information, advice and signposting, as well as support to individuals both before and after diagnosis.

Psychiatric services in the community

Devolution has encouraged divergence in the various services across the UK. In England, service provision is being defined by care pathways, which, besides diagnosis, should include access to the wider network of support. Specialist autism teams (SATs) are being established that can complement or are combined with an ADHD team to provide a more comprehensive neurodevelopmental service.

Varying in composition, their core membership usually includes psychology and nursing.

Local agreement needs to define the relationships between the adult mental health team, the specialist autism team and the community learning disability team. Although the last are usually familiar with autism, they may be excluded from working with people whose cognitive ability (e.g. as measured by the Wechsler Adult Intelligence Scale) lies within the normal range even though their functional ability (e.g. as measured by the Vineland Adaptive Behavior Scales) may come within the provision of the Adults with Incapacity Act (Scotland) 2000 or the exhortations of the Department of Health (Secretary of State for Health, 2001). There remains the risk that such vulnerable people will fall between the different mental healthcare contracts despite the statutory entitlement of all adults to access to psychiatric services. It is important therefore that there is explicit provision in each locality that extends beyond the diagnostic process and that encourages the coherent involvement of the wide range of agencies and services that will benefit the individual.

The great growth in specialist services, many in the independent sector, for the social care and education of people with autism, as well as in self-advocacy organisations, makes for a rich source of knowledge of the effects of autism and the resultant needs. However, this growth encourages out-of-area placement for individuals whose degree of disturbance has led to specific additional funding. Such placements are difficult to monitor and can be a significant financial burden for their sponsoring health economy. In addition, they dislocate the person even further from all that is familiar to them: their community, family and acquaintances.

The receiving authority can find itself encumbered with a provider and an individual, both of whom will need specialist support (including psychiatric

input). There is little formal machinery to ensure the involvement of, let alone any control by, local commissioners in such developments by the independent sector. The result can be local services, already overstretched and underfunded, that are unable or unwilling to respond. A specialist package of care for an individual with disturbed behaviour can result in an isolated house where it is difficult to ensure that the staff have proper managerial supervision and clinical support. Such a recipe, which produced the isolation and abuse of Winterbourne View (Flynn, 2012), also applies to community services. The risk may be reduced by bringing together specialist autism providers (whose past record of community care confirms their competence) and local teams, which should include those who will be called on to respond on a day-to-day basis (whether for adult mental healthcare, rehabilitation or intellectual disability, or the specialist autism team). For those coming out of hospital, there needs to be an adequate pre-discharge period of preparation for both the patient and the receiving staff. After discharge, individuals need sufficient time to ensure that they are able to acquire the skills necessary for independent living, a process that may be time-consuming but needs to happen at a pace geared to the individual. Failure is often the start of the damaging and expensive process of repeated placement breakdown.

Psychiatrists will find that it pays dividends to work closely with other agencies and to understand their key roles within a jointly agreed local care pathway. Examples of such approaches are the close collaborative working between old age psychiatry and social care for dementia, general adult psychiatry and primary care in the management of depression, and child psychiatry and education. Primary care has a key role in the initial recognition and consideration of whether to make a referral (the management of demand), in the physical care of vulnerable adults and in monitoring medication. Our GP colleagues wish us to remember that they often have a comprehensive overview of an individual's circumstances. They expect psychiatrists to communicate clearly and unambiguously about diagnosis and treatment, its purpose, benefits and drawbacks, particularly where the GP is asked to take up prescribing. Social care plays a key coordination role in commissioning for individual need; this might

include helping individuals to manage their finances, advocacy for people pressured by housing and employment problems (such as harassment by neighbours or being pushed to seek employment without recognition of disability) and dealing with the criminal justice system. There is also a responsibility to address the needs of carers and to prevent crisis and breakdown.

Whatever form the service takes, it is essential that there is adequate psychiatric input. Not all individuals will be seen by a psychiatrist, but if they are, they should have access to the psychiatrist's core skills:

- Diagnosis – particularly where the presentation is complex or involves a comorbid disorder, for it is essential not just to recognise autism but also to discount it, to have the breadth of understanding of other conditions that are associated with autism or that might mimic it. All psychiatrists need to be familiar with autism and, although their level of expertise will vary, they should have sufficient knowledge and experience to diagnose it when it is straightforward. Some will develop a greater degree of expertise necessary, for example, in more subtle cases where the diagnosis is less clear cut, or in more complex cases, obscured by comorbid disorder or unresponsive to standard approaches.
- The assessment of certain forms of risk.
- The recognition and management of comorbid conditions.
- The provision of legal opinion to the courts, both civil and criminal.
- The assessment and management of patients under the various legislations (e.g. the Mental Health Act 1983, the Mental Capacity Act 2005, the Mental Health (Care and Treatment) (Scotland) Act 2003).

Psychiatric treatment units

Autism itself does not require psychiatric treatment, let alone warrant admission, but treatment may be needed for comorbid disorder. The increased availability of specialist community placements has

brought a greater readiness to manage psychiatric disorder in the community. However, when hospital admission is required, the facilities need to be sufficiently autism-friendly to avoid undermining the treatment.

Whether as a day- or an in-patient, admission can be more daunting for someone with autism than for most: uncertainty, unfamiliarity, a loss of control and the challenge of coping with strangers all contribute. At present, few psychiatric units provide either the setting or the staffing levels necessary to prevent conflict and to protect an individual with autism from bullying and harassment. It is difficult for staff to understand characteristics such as sensory sensitivity, communication overload or the need for rituals, let alone to accommodate them. In addition, besides lacking appropriate psychoeducational programmes, many units use cognitive or group approaches that, without adaptation, are ill-suited to autism, which in turn may cause individuals to refuse therapy for reasons that they are unable to articulate.

Where admission is unavoidable, it should be to an area adapted to autism, suitable for both the constitutional needs of the individual and their psychiatric disorder. Such a setting (which includes people, buildings and programmes) should be structured, predictable and calm. Stimuli should be of low intensity and the overall aim should be to reduce emotional arousal. There should be regular routines, consistent responses, the use of clear (and preferably visual) communication, and a restricted number of people (whether staff or patients), so that the individual can get used to them. Staff, rather than relying on their intuitive responses, need to be consciously aware of the sensitivities and perspectives of someone with autism, the unit attuned to its individual patients rather than to some abstract conceptual group, and a high priority given to the relationships, both social and professional, with others involved with the individual. There needs to be an emphasis on staff training in autism and, to avoid stagnation, on developing relationships with other specialist autism services.

There are some individuals for whom even this will be insufficient. The intensity of their autism, with its associated perceptual sensitivity, emotional fragility

and need for predictability, can be such that they require an unusual degree of structure within a highly specialist environment that uses autism-specific programmes and additionally skilled, specialist staff. In addition to psychiatric treatment, this type of setting should be able to provide the therapeutic and educational programmes designed to minimise the disabilities of autism. Although a number of hospitals declare their interest and availability for individuals with autism, very few have the dedicated facilities necessary to meet such needs. Individual patients can find themselves on units where the ethos, training and experience is more appropriate to people who simply require an unusual degree of security or have a general intellectual disability.

A few individuals will be sufficiently violent or dangerous to warrant an extended hospital stay. For many, however, it is not unusual for their short-term admission to become extended when it is realised that, even after a lengthy period of admission, they are going to require a specialist community placement and substantial resources. For these, admission acquires a flypaper quality, trapping them in hospital until an exit route can be devised.

With the difficulty of developing new resources in the community, the reduction in the number of NHS hospital beds has led to a compensatory growth in the private sector for those that require extended hospital placement. While the response to Winterbourne View (Department of Health, 2012) is expected to change this, difficulties may come to the surface regarding the legality of the kind of care that can be provided safely in the community. Where behaviour is sufficiently violent to require frequent restraint, seclusion or involuntary medication, its imposition requires a legal authority that may be difficult in the community. In Scotland, the Adults with Incapacity (Scotland) Act 2000 facilitates the community treatment of such adults. In England and Wales, it is a matter of judgement how far this may be permitted under the Mental Capacity Act 2005 and the 2007 amendments to the Mental Health Act 1983, which made formal provisions by way of the Deprivation of Liberty Safeguards. In the end, it may be necessary to apply to the Court of Protection for this degree of authority.

Although the direction of development of services is determined by strategies, in practice they have tended to be shaped by the interests and enthusiasm of those involved locally (including a range of non-healthcare providers in the

independent sector) as much as by local need. As community care continues to evolve, innovation will require both flexibility and contractual clarity on the part of service commissioners and service providers.

Appendix: Instruments for identifying autism

This is a list of some of the instruments that have been used in the UK. Its purpose is to give clinicians a brief overview of the measures that may have been used to assess the people presenting to them. This account is neither definitive nor detailed: for that, readers should consult other reviews, such as Charman & Gotham (2013) and Stoesz *et al* (2011).

There are a large number of instruments and it is important to distinguish how they are being used:

- clinical use – where they provide a framework for gathering sufficient information to allow the clinician to arrive at a diagnostic decision
- research use – for example where the information is processed through an algorithm to arrive at a decision as to caseness
- screening – where a test is used to identify those who warrant further assessment.

It is important to recognise that instruments have often been developed for specific purposes or populations, with limited trials outside these; in other circumstances, their reliability may be unknown. Examples are where they:

- have been developed for a particular age group, such as children
- take a cross-sectional, here-and-now approach rather than a longitudinal view of how individuals and their symptoms have developed
- have been developed as screening/survey instruments and have not been validated for diagnostic use
- rely on limited testing, for example based on case v. non-case comparisons (i.e. samples containing almost no uncertainty), so that their estimates for sensitivity and specificity

may not apply to other populations (such as referred patients or groups at risk of ASD)

- focus only on symptoms selected for their diagnostic value (omitting those that do not discriminate effectively). Consequently, the instrument does not provide an overall description of the person's full range of characteristics.

Questionnaires

Australian Scale for Asperger Syndrome (ASAS)

A parent/teacher rating tool designed for older children who do not have a significant degree of intellectual disability (but, because of its public availability, it is used more widely). It has 24 graded questions and a 10-item behavioural checklist. It does not give scores or a cut-off, but does alert individuals, parents and teachers to the possibility of autism. Developed by Tony Attwood (www.aspergersyndrome.org/Articles/The-Australian-Scale-for-Asperger-s-Syndrome.aspx).

Gilliam Autism Rating Scale (GARS and GARS-2)

A parental/teacher checklist for people up to 22 years of age. It has 42 items divided into three sections (stereotyped behaviours, communications and social interactions) and takes 5–10 minutes to complete and score. It is advocated as a well-standardised USA screening instrument, but published research indicates that it is insufficiently sensitive to be an effective discriminant of ASD. The revised version is new and it is not yet clear whether the concerns about the earlier instrument have been resolved (Lecavalier, 2005).

Social Communication Questionnaire (SCQ)

(Previously known as the Autism Screening Questionnaire.) A 40-item questionnaire developed from the Autism Diagnostic Interview – Revised, (ADI-R), it comes in two versions (Lifetime and Current) for use with people over 4 years of age. It should be completed by the parent/carer (Berument *et al*, 1999). Developed by Michael Rutter, Anthony Bailey and Catherine Lord (www.hogrefe.co.uk/social-communication-questionnaire-scq.html).

Social Responsiveness Scale – 2 (SRS-2)

(Previously known as the Social Reciprocity Scale.) A 65-item questionnaire to be completed by a parent/teacher in less than 20 minutes. There is an adult module for those over 18 years of age. It gives a total score as well as scoring on five subscales (Constantino *et al*, 2003). Developed by John M. Constantino (www4.parinc.com/products/Product.aspx?ProductID=SRS-2).

Autism Spectrum Quotient (AQ) and Autism Spectrum Quotient – 10 (AQ-10)

The AQ is a self-report questionnaire that provides a summary score that indicates the likelihood of ASD. In practice, it requires a degree of insight; completion by an informant will often give a higher score (more autistic). It has a high false-positive rate when used in the general population, but is more accurate in adult mental health service patients.

The AQ-10 uses 10 of the AQ's more discriminatory items and is recommended by NICE (National Institute for Health and Clinical Excellence, 2012) to identify those who should have a more comprehensive assessment for autism.

The AQ and the AQ-10 are produced by the Autism Research Centre (www.autismresearchcentre.com/arc_tests).

Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)

An 80-item structured questionnaire completed by the clinician (but can be self-completed

with guidance). Recently developed, it has an acceptable level of sensitivity and specificity in adult patients attending a mental health service (Ritvo *et al*, 2011) (www.ncbi.nlm.nih.gov/pmc/articles/PMC3134766).

Social and Communication Disorders Checklist (SCDC)

A 12-item screening questionnaire for completion by parents, it is suitable for population surveys (Skuse *et al*, 2005). An adult version has yet to be validated.

Autism Behavior Checklist (ABC)

This questionnaire for completion by parents was designed for the diagnosis of autism in young children. It has good statistical underpinning for its original purpose, and people are now experimenting with its use for older children (Krug *et al*, 1980). Available from PRO-ED Inc (www.proedinc.com/customer/ProductView.aspx?ID=4219).

Diagnostic interviews

However detailed and structured the interview, the results can be misleading if the informants are determined on a particular outcome and the clinician insufficiently experienced.

Autism Diagnostic Interview – Revised (ADI-R)

A semi-structured 93-item interview designed to take a developmental history from parents so that there is a focus on the presentation in early childhood as well as the current state. It is a diagnostic instrument that excludes items not immediately relevant to this and, over 2–3 hours (with an additional 20 minutes for scoring), allocates each symptom a grade that can be used in a well-tested diagnostic algorithm (Lord *et al*, 1994). Designed as a research tool, it is internationally recognised and frequently referred to as the gold standard. Its use in research requires several days of formal training, but there is a self-teach training pack for clinical use. Available with self-training materials from Hogrefe (www.hogrefe.co.uk/clinical-and-educational.html).

Autism Diagnostic Observation Scale, 2nd Edition (ADOS-2)

A subject interview and observational measure that complements the ADI-R history. The interview, lasting 30–60 minutes (with an additional 20 minutes for scoring), is a combination of activities and conversation designed to elicit, describe and rate the symptoms of ASD using a standardised kit. A set of five modules cover the whole range of age and ability, the choice being determined largely by the level of expressive language. The individual's responses are graded with a numerical score, allowing the development of an algorithm, albeit restricted to social and communicative items (Lord *et al*, 2000). The scale's reliability and validity, achieved by an intensive training course, make it one of the main research tools, although it seems to be less sensitive with adults with Asperger syndrome (module 4). While its use in research requires several days of formal training, there is a self-teach training pack for clinical use available from Hogrefe (www.hogrefe.co.uk/clinical-and-educational.html).

Diagnostic Interview for Social and Communication Disorders (DISCO)

A structured interview that, like the ADI-R, gathers and synthesises information from a variety of informants, but rather than focusing on the diagnosis of autism, it makes a broader assessment of developmental disabilities. Favoured for general clinical use, it takes 2–3 hours to administer and requires several days of training. It provides numerical scores that contribute to a set of diagnostic algorithms (which do not equate to clinical diagnoses) and it is a reputable research tool. A shorter form, taking about an hour to administer, is being developed. Developed by Lorna Wing and Judith Gould (www.autism.org.uk/disco).

Developmental, Dimensional and Diagnostic Interview (3di)

A modular structured interview that uses a laptop computer to work through a variety of areas with an informant, usually a parent. Besides questions

that are specific to autism, it covers other mental states as well as demography, family background, developmental history and motor skills. The whole interview takes about 90 minutes and the computer immediately generates a structured report based on algorithms using a dimensional framework of symptom and diagnostic profiles for autism and common non-autistic comorbid conditions. Although devised to assess children of normal intellectual ability, it has been used across the range of age and ability and it has good validity against the ADI (Skuse *et al*, 2004). Its format lends itself to good reliability with limited interviewer training. There have been two approaches to abbreviating the face-to-face interview: parents can complete a pre-interview package of questionnaires that is then entered onto the computer, reducing the face-to-face interview to 45 minutes; or a shortened (53-item) version can be used. This has been validated against the ADI. Their use requires a 2-day training course (offered by the National Centre for High Functioning Autism at Great Ormond Street Hospital). An adult version is being developed.

Adult Asperger Assessment (AAA)

A semi-structured interview schedule that automatically incorporates (through an MS Excel file) the results of two questionnaires (the AQ and EQ) developed by the Autism Research Centre. It incorporates the DSM-IV criteria but also draws on additional symptomatology to give a higher threshold (Baron-Cohen *et al*, 2005) (www.autismresearchcentre.com/arc_tests).

Diagnostic Interview Guide for the Assessment of Adults with Autism Spectrum Disorder

Developed by the Royal College of Psychiatrists as an adjunct to a standard psychiatric interview, this is intended for use by psychiatrists working with adults with clear-cut autism, and is supported by an online training resource (although the latter is restricted to College members). Both can be accessed through www.rcpsych.ac.uk/traininpsychiatry/conferencetraining/courses/dirinfo.aspx.

Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS)

A well-validated and reliable structured instrument for interviewing the carers of people with an intellectual disability across the whole age range. This is being used as a research tool, particularly in The Netherlands, where it was developed. The background detail is given in Kraijer (1997).

Asperger Syndrome Diagnostic Interview (ASDI)

This brief interview explores six key domains that Gillberg has associated with Asperger syndrome. It is described as a screening rather than a diagnostic instrument (although often cited as the latter) (Gillberg, 2001).

Childhood Autism Rating Scale (2nd Edition) (CARS-2)

A useful framework to rate behaviour across 13 domains, it was geared to DSM-III. A new edition includes two rating scales – the standard version (CARS2-ST), comparable to the original CARS, is for use with young children or those with communication or intellectual difficulties; and the high-functioning version (CARS2-HF), for more able individuals, older than 5 years and verbally fluent. There is also a separate questionnaire for parents/caregivers. A 7-point scale is used to allocate a score to each domain, allowing a total score to be calculated that, at its extremes, is probably valid. Developed in the USA by Eric Schopler and colleagues, it is self-taught from booklets that, in the UK, may be obtained from Winslow Press (www.winslowresources.com) and Hogrefe (www.hogrefe.co.uk/clinical-and-educational.html).

Handicaps, Behaviour and Skills (HBS) schedule

An early diagnostic scale produced by Wing & Gould which was superseded by their development of the DISCO (Wing, 1996). It assessed skills as well as symptoms.

Wing Autistic Disorder Interview Checklist (WADIC)

Effectively, this is a shortened HBS that focuses on the symptoms of autism; it is relatively brief and is in the public domain (Wing, 1996).

Instruments to assess associated developmental disabilities

A number of instruments are available to assess some of the specific developmental disabilities that have been associated with ASD.

Autism Research Centre tests

The Autism Research Centre (Cambridge, UK) has developed a series of tests of individual abilities (www.autismresearchcentre.com/arc_tests). Some of these are:

- **Autism Quotient (AQ)** – this is described above.
- **Empathy Quotient (EQ)** – a 40-item self-completion questionnaire, this provides a summed score that is a measure of the person's ability to think and feel what it is like to be in another person's shoes.
- **Systemizing Quotient (SQ) – the Revised Cambridge Personality Questionnaire** – a 75-item self-completion questionnaire.
- **Faces Test** and **Eyes Test** – assess the ability to recognise a series of emotions from faces or eyes (Baron Cohen *et al*, 2001).
- **Faux Pas Recognition Test** – a series of simple stories, each with several questions that test a variety of factors: whether the person has understood the story, and their ability to understand another's viewpoint, to understand social situations and rules, and to recognise mistakes.
- **Social Stories Questionnaire (SSQ)** – ten stories, each divided into three parts, that assess the person's ability to judge the social appropriateness of the characters' actions.

Dewey's Social Stories

A way of identifying difficulties with social relationships and situations by telling the person a series of short stories and asking questions about their perception of certain aspects (Dewey, 1991).

Adolescent/Adult Sensory Profile

A 60-item questionnaire developed by Catana Brown and Winnie Dunn to provide a systematic analysis of an individual's sensory thresholds and responsiveness. Although labelled a self-questionnaire, it seems that, given its American origin and phrasing, reliability requires that it be administered as an interview by a clinician. Published in the UK by Pearson (www.pearsonclinical.co.uk).

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