

CR228

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# The psychiatric management of autism in adults

COLLEGE REPORT

# Contents

<b>Working group</b>	<b>5</b>
<b>Executive summary</b>	<b>7</b>
<b>Recommendations</b>	<b>9</b>
<b>Chapter 1: Introduction</b>	<b>10</b>
1.1 The purpose of this report	10
1.2 Concepts and terminology	11
<b>Chapter 2: Epidemiology</b>	<b>13</b>
2.1 Prevalence of autism	13
2.2 Prevalence of co-occurring conditions	14
Neurodevelopmental conditions	14
Gender dysphoria (DSM 5) / Gender incongruence (ICD-11)	14
Psychiatric disorder	15
Genetic disorder	16
2.3 Prevalence of offending	16
<b>Chapter 3: Policy</b>	<b>18</b>
3.1 England	18
3.2 Wales	19
3.3 Scotland	19
3.4 Northern Ireland	20
3.6 The Isle of Man	20
<b>Chapter 4: Recognition, diagnosis and assessment</b>	<b>21</b>
4.1 Recognition	21
4.2 The nature of diagnosis and assessment	24
Diagnosis	24
Assessment	24
4.3 Distinguishing co-occurring psychiatric disorder	25
Anxiety	25
Depression and suicide	26
Post-traumatic stress disorder (PTSD)	27
Burnout	27
Schizophrenia	27

Eating disorders	30
Extreme/pathological demand avoidance (PDA)	30
4.4 The purpose of diagnosis	31
4.5 The process of diagnosis	32
4.6 Tests for autism	34
<b>Chapter 5: Legal aspects of psychiatry</b>	<b>36</b>
5.1 Mental capacity and consent	36
5.2 The ability to bear witness	37
5.3 Offending behaviour	38
5.4 Disposal in the criminal justice system	40
<b>Chapter 6: Management</b>	<b>42</b>
6.1 The management of autism	42
6.2 Psychiatric management	42
Medication	42
Psychological treatments	43
<b>Chapter 7: Services</b>	<b>45</b>
7.1 Services other than health	45
7.2 Psychiatric services in the community	46
7.3 Psychiatric treatment units	49
<b>Appendix 1: Instruments contributing to assessment</b>	<b>51</b>
Questionnaires	52
Australian Scale for Asperger Syndrome (ASAS)	52
Gilliam Autism Rating Scale (GARS and GARS-2)	52
Social Communication Questionnaire (SCQ)	52
Social Responsiveness Scale – 2 (SRS-2)	52
Autism Spectrum Quotient (AQ) and Autism Spectrum Quotient – 10 (AQ-10)	53
Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R)	53
Social and Communication Disorders Checklist (SCDC)	53
Autism Behavior Checklist (ABC)	53
Interviews	53
Autism Diagnostic Interview – Revised (ADI-R)	53
Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2)	54
Diagnostic Interview for Social and Communication Disorders (DISCO)	54

The Handicaps, Behaviour and Skills (HBS) schedule	54
The Wing Autistic Disorder Interview Checklist (WADIC)	54
Developmental, Dimensional and Diagnostic Interview (3di)	54
The Autism Clinical Interview for Adults (ACIA)	55
Adult Asperger Assessment (AAA)	55
Diagnostic Interview Guide for the Assessment of Able Adults with Autism Spectrum Disorder	55
The Neuro-developmental Section of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN ND)	55
Scale of Pervasive Developmental Disorder in Mentally Retarded Persons (PDD-MRS)	56
Asperger Syndrome Diagnostic Interview (ASDI)	56
Childhood Autism Rating Scale (2nd Edition) (CARS-2)	56
Instruments to assess associated developmental disabilities	57
The Autism Research Centre tests	57
Dewey's social stories	57
Adolescent/adult sensory profile	57
<b>Appendix 2: Psychiatric training objectives</b>	<b>58</b>
Introductory statement	58
Learning outcomes [for all psychiatrists]	58
<b>References</b>	<b>61</b>

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# Executive summary

The *Introduction* (Chapter 1) sets out the purpose of this report which is about the recognition and management of autistic adults without intellectual disability; ‘autism’ being used here to include autism spectrum disorder/condition. It is the latest version of a report first produced in 2006 (CR136) and revised in 2014 (CR191).

The report is part of the College’s broader programme to improve mental health services for autistic adults, and reflects the increasing expectation that all services should make the necessary adaptations to enable their access. The focus is the role of psychiatrists and their contribution to the care of those who come to their services. It applies to all areas of adult psychiatric practice including old age, liaison, forensic and rehabilitation psychiatry as well as adult mental health, whether in the community or in hospital. Its aim is to improve psychiatric practice in the UK and it includes a list of *suggested training objectives for psychiatrists* (Appendix 2). It takes a broad, pragmatic approach, drawing on clinical expertise and opinion to inform its conclusions. Intentionally short, it is not a text about the wider aspects of autism and it does not replace other, more detailed documents such as the guidelines issued by the National Institute for Health and Care Excellence (NICE (National Institute for Health and Care Excellence), 2012) and the Scottish Intercollegiate Guidelines Network (SIGN, 2016).

The evidence underpinning this area of work is very limited. Further research is a high priority and psychiatrists should facilitate and engage in such research wherever possible.

Chapter 2 outlines the *Epidemiology* of autism, present in about 1% of the adult population. It is closely associated with other neurodevelopmental conditions, particularly attention deficit hyperactivity disorder (ADHD), and with psychiatric disorder (especially anxiety and depression). This means that it is present in about 5% of the users of UK mental health services. Here it can pass unnoticed, overshadowed by the presence of co-occurring disorders, as well as attracting misdiagnoses as varied as schizophrenia, obsessive-compulsive disorder and personality disorder (notably borderline personality disorder), such errors possibly more likely in women whose autism may be less readily recognised.

Chapter 3, on *Policy*, sets the scene within which specific services have developed across the UK. There are summaries of the different approaches adopted, which started with the Autism Strategies in Wales (2008) and Scotland (2011), and the Autism Act in England (2009) and Northern Ireland (2011). Although their subsequent evolution has differed in detail and pace, their intent has been to ensure better services and outcomes for autistic people

*The recognition, diagnosis and assessment of autism*, (Chapter 4) occupies a third of the report, reflecting its importance in psychiatric practice. The chapter sets out a range of indicators that might alert a clinician to the presence of autism,

before going on to describe the features that might help distinguish it from a number of specific, co-occurring psychiatric disorders including:

- *emotional disorders*, such as anxiety, whose identification can be hindered by a variety of communication difficulties, notably a limited ability to label or describe internal states;
- *depression*: while the behavioural changes may be recognised autism complicates the assessment of suicidality, a major contributor to the increased mortality associated with this group;
- *burnout*, the informal label for a state of exhaustion that comes from the stress of coping with difficult sensory and social settings; it is distinct from anxiety and depression;
- *schizophrenia*, a recurrent problem in differential diagnosis, requiring the clinician to draw on the individual's earlier developmental patterns (where available) as well as (listed) distinguishing characteristics;
- *eating disorders*, where it is important to distinguish between avoidant/restrictive food intake disorder (ARFID) and anorexia nervosa, both of which are associated with autism.

The threshold for the diagnosis of autism will vary depending on *the purpose of the diagnosis*, which may be for research, clinical or administrative reasons. However, there are substantial differences across different locations and clinics and the report therefore examines *the process of diagnosis*. The chapter's emphasis is on how the psychiatrist might modify their circumstances and techniques to make the most of any interview with an autistic person.

The chapter ends with an account of *the tests used to identify and assess autism*, with a summary of a number of interviews and questionnaires (Appendix 1).

Chapter 5 moves on to the more formal assessments grouped under *the legal aspects of psychiatry*. It lists some of the issues that may complicate the assessment of *mental capacity*, and thereby the validity of an individual's *consent to treatment*, and suggests further measures to supplement the interview techniques listed in the previous chapter.

It describes the factors that might potentially affect the ability of an autistic person to give an accurate and reliable account of an event and to *bear witness*, and suggests ways of reducing their influence.

While *offending behaviour* in an autistic person may well be affected by co-occurring ADHD (and helped by its treatment) there are other contributory elements, and all need to be taken into account by a management plan, the latter including various avenues of *disposal in the criminal justice system*.

Chapter 6, on *Psychiatric management*, in the main is about those disorders that frequently co-occur with autism and which might be expected to be managed by standard adult services, using standard treatments, albeit with appropriate adjustments to accommodate the autism. Thus, psychological approaches can



be adapted to differences in communication, social imagination and empathy, and while the usual indications for medication apply, it is to be used more cautiously and with the anticipation of an unusual response.

The presence of autism requires a multidisciplinary approach including, for example, psychology, speech therapy and occupational therapy. In addition, and subject to the agreement of the autistic person, families and carers need to be included.

The management of autism itself is chiefly about the provision of the education, training and social support/care required to improve the person's ability to function in the everyday world. Although these fall outside the scope of this report, the psychiatrist and their team need to work collaboratively with these *services* (Chapter 7), potentially wide ranging but very uneven in their provision.

Health's remit is limited in the main to the diagnosis of autism and the management of co-occurring psychiatric disorder. The latter is often long-term and the population is one in which many find it difficult to access services: ill-served by unfamiliar staff and time-limited case management, they require the infrastructure appropriate to chronic conditions. It is essential that the mental health team knits into the wider, multiagency network in which the substantial part is taken by other services, such as education, social services and the voluntary and independent sectors.

## Recommendations

1. All psychiatrists should continue to improve their expertise in autism through training and experience, and particularly, by familiarity with the autistic world.
2. All psychiatrists should be able to recognise and treat psychiatric disorder in autistic people, distinguishing it from the features of autism, and be able to make the appropriate adjustments to their treatment, care and follow-up.
3. All psychiatric services should aim to have a close working relationship with their local specialist autism resources.
4. There should be a programme to improve diagnostic consistency across the UK, something that requires those involved to develop networks, an initiative which the College should support.
5. All psychiatrists should facilitate and engage in autism research wherever possible and encourage the meaningful involvement of autistic people in its design and development. They should explore what options are open locally, nationally or internationally and decide how best to link in - one example is Autistica whose Discover network shares new findings, events and opportunities for research ([www.autistica.org.uk/get-involved/take-part-in-research](http://www.autistica.org.uk/get-involved/take-part-in-research)).

# Chapter 1: Introduction

Throughout this report, the term 'autism' is used to include all conditions on the autism spectrum, whether autism spectrum disorder (ASD), autism spectrum condition (ASC), or other terms such as Asperger syndrome, atypical autism or pervasive developmental disorder.

In line with current practice, this report uses identity-first language ('an autistic person' rather than 'a person with autism').

## 1.1 The purpose of this report

This document is a part of the College's broader programme to improve the mental health services for those autistic adults who do not have a generalized intellectual disability. It focuses on the role of psychiatrists while appreciating that theirs is only one component of a much broader approach. It is intentionally short, restricted to practice in the UK, and takes a broad, pragmatic approach, drawing on clinical expertise and opinion to inform its conclusions. It is intended to complement other, more detailed documents, such as the guidelines issued by the National Institute for Health and Care Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) (NICE, 2012; SIGN, 2016).

It is recognised now that most autistic people are adult, do not have an intellectual disability and are likely to be undiagnosed. Of those known to services, many have a wide variety of co-occurring physical and mental conditions. This association means that, for many, their first professional encounter will be with adult psychiatry (whether general, rehabilitation, forensic, old age, liaison or some other specialty). Some will have problems that relate immediately to autism (including those seeking a confirmatory diagnosis), but most will come with the symptoms of an assortment of psychiatric disorders. The context will complicate their presentation (and management) further; this includes where and how they live, the people and the services available.

While there are specialist autism services, they are patchy and with limited funding and remits. Even where such a service exists, the clear legal expectation is that an autistic person has the same right as anyone else to access a generic physical and mental health service if their co-occurring condition meets the threshold criteria for that service. Despite this, it is common for clinicians to use autism as a justification for denying someone treatment for a psychiatric disorder, attributing all their symptoms to autism.

This document is to help psychiatrists to recognise autism (distinguishing it from co-occurring disorder) and to treat their patients appropriately, making reasonable adjustments and avoiding discrimination. Together with other resources (such as clinical discussion and online packages), it will help them to meet their statutory training requirements related to autism.

## 1.2 Concepts and terminology

*Autism Spectrum Disorder (ASD)* is one of a range of neurodevelopmental conditions defined in DSM-5 and ICD-11 (American Psychiatric Association, 2013; World Health Organisation, 2018) with the former giving a particularly good description of its characteristics. Diagnosis requires the combination of:

- characteristic difficulties in reciprocal social relationships and communication
- a history of restricted, repetitive or stereotyped behaviour, interests and activities associated with difficulties with flexibility and a consequent preference for predictability and routine; this group of symptoms, which includes anomalous responses to sensory stimuli, is summed up as 'Restricted, Repetitive Behaviour' (RRB)
- childhood onset; although the individual's difficulties usually are recognised early, there may be a delay until their coping strategies are outstripped by an increase in social expectations (e.g. on the transitions through school and beyond to independent living, further education or employment); in the older adult, there may be little early history available so that it may not be possible to determine the time of onset, but this should not preclude a diagnosis.

In common with other neurodevelopmental disorders, autistic characteristics change with age and circumstance and their presentation is complicated further by co-occurring developmental and psychiatric disorders.

By their nature, accounts of the diagnostic features will be selective, omitting a wide range of associated characteristics, skills and strengths. For example, a fascination with systems and patterns, an attention to detail, and the ability to concentrate for long periods may be expressed in strong and persistent interests which can be conducive to creativity and originality. Unusual talents in areas such as memory, visual functioning, and musical processing may pass unrecognised unless very pronounced.

*Asperger syndrome*, only included in the international diagnostic classifications in the 1990s, was distinguished by the presence of relatively fluent speech and the absence of a general intellectual disability. The category could not be distinguished consistently and newer classifications have discarded it, along with other subtypes of autism. However, many autistic people continue to use Asperger syndrome as a useful label to identify themselves.

It is unknown how often a similar social communication difficulty occurs in the absence of RRB, past or present. Labelled as *Developmental Language Disorder* (ICD-11) or *Social (Pragmatic) Communication Disorder* (DSM-5), it is categorised currently as a separate communication disorder rather than as a variant of autism.

There is a great variability in the nature and intensity of the constellation of features that go to make up autism. The result is a continuum of presentation that shades

from severe and obvious disability, through variants (which, although subtle, may still bring social disadvantage) to blend into traits found in the general (neurotypical) population ('neurotypical' being a widely used term to identify the absence of significant neurodevelopmental disorder). It is a clinical judgement as to whether an individual's characteristics achieve the diagnostic threshold of a significant impairment in their current functioning across a variety of settings. It will depend not only on their innate characteristics, but also on their current circumstances and mental state. As with all psychological and neurodevelopmental conditions, symptoms may be minimal in supportive settings but become amplified by distress, leading to a deterioration in everyday functioning and, for some, 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: their inherent difficulties leave autistic individuals less able to cope with the messiness of the everyday world.
- autism as a *disability*, a condition that requires specialist remedial education or environmental adaptations to help the individual to enjoy as full and independent a life as possible.
- autism as one element in the range of *neurodiversity*, an innate difference (much as someone might be left-handed) rather than a deficit; the difference becoming prominent in an alien, socially complex world attuned to neurotypical normality; here, it is better expressed by the term 'condition' rather than 'disorder.'

These concepts are not mutually exclusive and, depending on their circumstances and needs, individuals, family members, service providers and researchers will draw on whichever is of most use to them at the time.

There was a similar debate as to the nature of 'intellectual disability' (the term used in this report). This preceded the introduction of Intellectual Disability Disorder (IDD) by DSM-5 and Disorder of Intellectual Development (DID) in ICD-11, both terms which identify with health disorder.

# Chapter 2: Epidemiology

## 2.1 Prevalence of autism

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

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. Changing concepts and diagnostic practice over the last thirty years have combined with greater awareness to increase the number of people identified as autistic. Although there is an association with Intellectual Disability (ID), the current estimate is that autism is present in at least 1% of the general population, of whom most are adult. This is derived from a case-finding population survey in England (after excluding those with moderate/severe intellectual disability) and startlingly few had been diagnosed previously or were known to services (Brugha et al., 2011). While a number of surveillance programmes report higher prevalence figures, their validity is subject to their methodology.

An increased prevalence of autism has been reported in groups that are at a socio-economic disadvantage (Rai et al., 2012b) or migrant (Magnusson et al., 2012), factors that might contribute to a greater prevalence in an Afro-Caribbean population in higher income countries (Goodman and 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).

Autistic characteristics are usually most pronounced in early childhood, becoming less obvious as the individual moves into adulthood, whether as a result of innate maturation, learned compensation or a move into less demanding circumstances: milder characteristics may become sub-clinical, only to emerge in a crisis or an adverse environment (Balfe et al., 2011; Fein et al., 2013). Although the trajectory in later life has yet to be determined (Mukaetova-Ladinska et al., 2012), the adult general (household) population survey did not find prevalence to change significantly with age (Brugha et al., 2012). All the same, those whose traits fall short of the diagnostic threshold may well retain disabilities in areas such as perception, cognition, communication and motivation which, although 'hidden', can be a substantial hindrance in everyday life.

While 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, higher figures might reflect an unusually supportive community (Engstrom et al., 2003; Farley et al., 2009; Howlin et al., 2013).

## 2.2 Prevalence of co-occurring conditions

Autistic people are at greater risk of co-occurring psychiatric disorder (Mandell, 2018). Therefore, although autism is present in about 1% of the general population, it is encountered in 3-5% of mental health service users (Brugha et al., Accepted for publication; Nylander and Gillberg, 2001), its presentation and management being affected by their co-occurring disorders. These will colour, for example, their communication, flexibility and ability to engage in the clinical process; overshadowed, the autism may go unnoticed or, conversely, its characteristics be so amplified by stress that everything is ascribed to autism and any other issues are missed.

### Neurodevelopmental conditions

Autism is one of a range of neurodevelopmental conditions ranging from specific learning disabilities (e.g. in language, dyslexia or dyscalculia) to more complex syndromes that include attention deficit hyperactivity disorder (ADHD) and developmental coordination disorder (DCD). Autism is associated with these other conditions, ADHD being present in 30% of autistic children (as against 4% in the general population), tics in 10% (vs 6%), developmental coordination disorder in 70% (vs 5%) and epilepsy in 5% (vs 1%). The data for adulthood is more limited, but most neurodevelopmental disorders improve with age and, in the general population, ADHD reduces to about 2.5% (Simon et al., 2009) and tics to 0.7% (Schlander et al., 2011). We do not know how the presence of autism affects this pattern of change, but there are indications that ADHD is present in 30-45% (Polderman et al., 2014) and epilepsy in 5% of those autistic adults who do not have an intellectual disability (Rai et al., 2012a; Tuchman, 2013).

The elements that combine to give a condition are common to several conditions rather than being specific to one. For example, inattentiveness and distractibility, central to a diagnosis of ADHD, are also associated with autism as is compulsive behaviour, a component of Tourette syndrome as well as of obsessive-compulsive disorder. Speech anomalies, seen in developmental speech disorders, are associated with autism while limited theory of mind (mind blindness) occurs not just in autism, but also in schizophrenia and where there has been early loss of sight or hearing. The earlier perception of disorders as well-defined, discrete constellations of symptoms has blurred with the growing recognition of the extent to which their symptom profiles overlap (Ronald et al., 2006). A categorical diagnosis provides a caricature of someone whose complex mix of skills and difficulties requires a broader, more descriptive diagnostic assessment.

Hearing anomalies are more frequent in autism than in the general population and, obscured by autistic symptomatology, are more readily missed (Demopoulos and Lewine, 2016). There is a closer association with congenital blindness (Ashtarikiani, 2015).

### Gender dysphoria (DSM 5) / Gender incongruence (ICD-11)

Autistic traits appear over-represented in gender identity clinics and it has been suggested that there may be an association (Glidden et al., 2016). Overall the assessment and management of gender dysphoria should be in line with existing guidance (Royal

College of Psychiatrists, 2012) and, although the neurodevelopmental state may be relevant, it should not hinder access to a gender identity service.

## Psychiatric disorder

The association with psychiatric disorder may stem partly from an adolescence characterised by victimisation and bullying (Balfe and Tantam, 2010) affecting the development of self-esteem, social confidence, identity and the potential to live independently. Autism is over-represented among individuals presenting with eating disorder (Berkman et al., 2007) (see [p30](#)) and also with substance abuse (Butwicka et al., 2017).

**Mood and anxiety disorders** are particularly frequent, notably generalised anxiety disorder, agoraphobia, social phobia and obsessive-compulsive disorder (Joshi et al., 2013; Lever and Geurts, 2016; Russell et al., 2016) and depression and suicidal thoughts (Cassidy et al., 2014; Hudson et al., 2018). There is a wide variation in prevalence depending on the population studied (a community sample of autistic people, referrals to an autism service or those attending a mental health service) and the methodology used to identify the disorder (an autistic person may well put an unusual interpretation on the items in an unadapted survey instrument). However, meta-analysis suggests the lifetime expectancy to be about 40% each for depressive and anxiety disorders (Hollocks et al., 2019).

**Schizophreniform psychoses** are more frequent in autistic people (Selten et al., 2015) but the extent to which autism signals a predisposition is unclear as the issue is clouded by similar symptomatology and shared risk factors (King and Lord, 2011; Palmen and Van Engeland, 2012). Further blurring this are brief psychotic episodes (induced by severe stress and responsive to stress reduction and antipsychotics) which may be misdiagnosed as (more chronic) schizophrenia. The clinical distinction is discussed later (Table 1 on [p28](#)).

Bipolar affective disorder is also more frequent in autism (Selten et al., 2015), with the potential for a misdiagnosis of schizoaffective disorder.

**Catatonia** is an ill-defined syndrome that can occur with schizophrenia but also with other disorders, including autism. Catatonic symptoms run through neuropsychiatry (Cavanna et al., 2008) and characteristics such as stereotypies, complex mannerisms, echolalia, difficulty in initiating voluntary actions (including speech), unusual slowness, passivity and freezing are not unusual in autism and can become severe enough to interfere with everyday functioning (Dhossche, 2014; Rosebush and Mazurek, 2010).

Similarities in presentation may cause autism to be mistaken for a **personality disorder**, most frequently emotionally unstable/borderline, schizotypal, or obsessive-compulsive in form (Smith and Hobson, 2013). 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). At the same time, the presence of autism does not exclude a concurrent diagnosis of personality disorder (Rydén et al., 2008).

Finally, besides the increased likelihood of autistic traits in the immediate family of an autistic person, the clinician must be alert to the increased risk of psychiatric disorder, the result of shared genetic predisposition rather than simply the effect of caring for someone with autism (Daniels et al., 2008; Piven and Palmer, 1999). Multiple sources of stress can interact to affect both the individual and those around, contributing to a complex domestic dynamic.

## Genetic disorder

While the heritability of autism is about 80–90%, with increased traits in parents and a 10–20% risk of recurrence in a sibling, the role of genetic factors is complex. Certain rare syndromes are associated with autistic symptomatology, sometimes accompanied by intellectual disability (e.g. neurofibromatosis, tuberous sclerosis, Klinefelter syndrome, fragile X syndrome and Turner syndrome), and represent a single genetic variant with a large effect. In others who do not have a recognised syndrome, advances in genetic testing are identifying similar ‘rare variants of large effect’ in the form of an increase in pathogenic copy number variations (CNVs), or even smaller changes to the genome. Such variants are likely to be more prevalent in those with significant co-occurring developmental difficulties, such as intellectual disability and/or epilepsy. For many without such difficulties, polygenic variation is more likely to play a role (as it is with any continuously distributed trait in the population), with a low yield from genetic testing.

Current recommendations are therefore only to test those with significant dysmorphic features, congenital anomalies, or co-occurring developmental difficulties. At the same time, this is a fast-changing field which should be reviewed regularly with the regional genetics centre.

## 2.3 Prevalence of offending

Most autistic people are law-abiding (and even rule-bound) and there is no real evidence to suggest that they are more likely to offend than others. There is a debate as to how far this might be offset by the few whose characteristics may predispose them to entanglement with the law (see 5.3 Offending behaviour on [p16](#) for examples) (Barry-Walsh and Mullen, 2004). In the absence of systematic community studies, our present knowledge comes from a slowly growing number of clinical studies, reports in the professional literature, and a small number of cases that have received extensive media coverage. While there is the suggestion that a small proportion of autistic people may commit more serious and idiosyncratically motivated crimes with a disproportionate degree of violence (Mouridsen, 2012), any link appears to be a consequence of an association with ADHD rather than with autism itself (Heeramun et al., 2017).

The selection bias of the process that identifies someone as an offender is so variable as to be a matter of chance. 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 (Hare et al., 2000; Scragg and Shah, 1994), but the specialist nature of these settings forbids extrapolation to other hospitals or prisons. A study in Scottish prisons revealed the difficulty in identifying autistic individuals, let alone estimating its prevalence (Robinson et al., 2012).

# Chapter 3: Policy

Widespread recognition of autism in adults without an intellectual disability has led to a shift in its public perception and a demand for better resources, greater awareness, and a higher level of professional expertise. It has become clear that, rather than an isolated condition, an autistic individual will have a personal profile that includes a mix of neurodevelopmental disabilities, strengths and skills which, in turn, affects their further development. In addition, there is the likelihood of developing a co-occurring psychiatric disorder, affecting both the presentation and the management plan, and reducing the ability to manage the activities of daily living, potentially to the point of needing long-term support. 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.

Disorder or disability should not bar anyone from access to any clinical services, and autistic individuals should be managed within mainstream mental health services with suitable adjustments for autism. For some, these services will need to be buttressed by more specialist provision. Consequently, all mental health services, including specialist services (e.g. psychotherapy, forensic and old age psychiatry), must consider how they will meet the needs of their autistic patients effectively, and from where they will obtain specialist support.

## 3.1 England

The Autism Act 2009 was followed by three documents which include a Strategy and statutory guidance (Department of Health, 2010a; Department of Health, 2010b; Department of Health, 2014) placing a legal obligation on local authorities and all NHS organisations to develop services, overseen by a local ASD strategy group. Commissioning guidance has been issued (Department of Health, 2015; Department of Health and Social Care, 2019) as well as clinical guidelines on diagnosis and management, and service quality standards (NICE, 2012; NICE, 2014).

A process of collaborative commissioning which includes both health and social care, and is based on joint strategic needs assessments (JSNAs), has produced five-year local sustainability and transformation plans (STPs). For autism, these plans should make for equitable access to mainstream services (through reasonable adjustments) as well as more specific provision including a pathway to diagnosis, appropriate treatment, support (in areas such as occupation, housing and leisure services) as well as training for all staff working for health, social care, education and independent providers.

In 2018, the Department of Health and Social Care established Task and Finish Groups to implement one of five themes taken from the Autism Strategy.

Abusive care in Winterbourne View led to the start of Transforming Care in 2012, a programme to improve community services for learning difficulties and autism with the

aim of curtailing inappropriate hospital admission. In 2019 NHS England made autism and learning disabilities a clinical priority for the NHS.

The Care Act (2014) made local authorities responsible for the welfare of both carers and service users and paved the way for statutory guidance on safeguarding vulnerable adults (Department of Health and Social Care, 2017).

## 3.2 Wales

The Autistic Spectrum Disorder (ASD) Strategic Action Plan (Welsh Assembly Government, 2008) was the first of the specific autism strategies in the UK. A 10-year programme with ring-fenced funding, it set out key actions, which included the establishment of local stakeholder groups and autism leads. An All Wales Network for Adults was established to provide diagnosis and support, irrespective of cognitive ability, and its revision in 2015 commissioned Integrated Autism Services in all areas and issued a competency based tiered training strategy. The same year the recurrent funding for an ambitious Children and Young People's Programme included a focussed neurodevelopmental workstream. A draft Code of Practice for the delivery of Autism Services has been issued for consultation, but an Autism (Wales) Bill was rejected by the National Assembly. However, the Wales Mental Health Measure (2012) provides a statutory framework for how people with mental health problems (including all in-patients) access and receive services.

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

## 3.3 Scotland

The Scottish Strategy for Autism (Scottish Government, 2011) set out 26 recommendations, to be jointly delivered by local and national government over a decade. Initial actions included a mapping project to determine areas of good practice throughout Scotland; the initial funding of six 'One Stop Shops' around Scotland (in collaboration with three major autism charities); the establishment of a Development Fund for individual project applications; and direct funding to each Local Authority in Scotland to develop local autism strategies and action plans. Funds from the Strategy also supported an initiative to investigate and ultimately reduce waiting times for diagnosis (Autism Achieve Alliance, 2014) and the development of the Autism Training Framework, which details the knowledge and skills required by those working in health and social care at different levels of autism expertise (NHS Education Scotland, 2014).

A refreshed Scottish Strategy for Autism was launched in 2018 with four major strategic outcomes, labelled *A Healthy Life, Choice and Control, Independence, and Active Citizenship*.

Guidelines were published in 2016 on the assessment and management of ASD (SIGN, 2016).

## 3.4 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). The multidisciplinary Regional Autistic Spectrum Disorder Network, established to implement the Action Plan, developed the Autism Adult Care Pathway (2013) as part of the service redesign to improve autism care, and guide commissioning, in Northern Ireland.

Delay and even deterioration in services led the National Autistic Society and Autism NI to publish *Broken Promises* in 2016 which urged that the Northern Ireland Assembly should implement the Autism Strategy in full, with the genuine participation of autistic people and their families and a clear accountable process for overseeing the implementation. Unfortunately, the Assembly was suspended shortly afterwards but, with its present resumption, it is hoped that this will come about.

## 3.5 The Channel Islands

**Jersey** has 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.

**Guernsey** is developing a similar service model.

## 3.6 The Isle of Man

There is no specific provision for autism in the legislation.

# Chapter 4: Recognition, diagnosis and assessment

## 4.1 Recognition

Many people have autistic traits and it is a clinical judgement whether these are sufficient in number and intensity, as well as in their impact on everyday functioning, to warrant a diagnosis of autism. The definitive characteristics are set out in international classifications (American Psychiatric Association, 2013; World Health Organisation, 2018), and national guidelines (NICE, 2012; SIGN, 2016). Given autism's dimensional character and the complexity of psychiatric symptoms in patients presenting to mental health services, the clinician should be sensitive to indicators in the following areas:

*Differences in social interaction:* These might include social awkwardness, restricted social responsiveness, and a limited ability to take part in meaningful, to-and-fro conversation, particularly in groups. A reduced intuitive understanding of how others might think or feel may emerge as a difficulty in understanding the nuances of social situations, a tendency to make social mistakes, or an apparent lack of concern for others. In the longer term, there may be difficulty in making and maintaining reciprocal friendships (distinct from the ability to make – but not retain – new acquaintances). Wherever possible, it is essential that the clinician gets accurate accounts of the individual's social relationships and interactions in different settings (e.g. at work and at home) and particularly how they manage more demanding situations.

*Communication differences and difficulties:* Difficulties with *non-verbal expression* can show in an unusual use of gaze, facial expression or gesture – elements which may be poorly integrated with each other as well as with what is being said. (The lack of communicative gaze is distinct from the persistent downcast gaze that may be seen in shyness or depression). Speech may have a pedantic correctness, lack vivacity, be unusually even in pitch and pace or consistently too loud or too soft.

The mismatch of emotional expressiveness is dangerously misleading. Anxiety can be masked by a fixed smile, an annoyed frown or an angry response, any of which can lead to serious misunderstanding. Many appear relatively impassive, giving a matter-of-fact account of their predicament without the facial expression, gesture or other signals that might indicate their distress. Others, trying to blend in with what goes for normal in their culture, may use exaggerated expression and gesture, with the result that they appear histrionic or 'just not right'.

There can be equivalent difficulties with *non-verbal comprehension* and an autistic person, unable to interpret a speaker's facial expression or tone of voice as indicating irony, sarcasm or humour, can be left to take what is being said literally.

*Verbal communication* is usually less problematic, particularly if the material is written rather than spoken. However, misunderstandings may reflect a literal interpretation of what someone has heard, and slow auditory processing (showing in lengthy delay before responding) can leave the individual struggling to grasp the sense of what is being said, even if they can echo the words. A frequent and natural pitfall is the innate assumption that, should someone sound fluent and coherent, this will be matched by good comprehension. Another trap is to assume that because someone can cope with a structured, question and answer dialogue, they can cope with informal conversation. The clinician must guard against these and check regularly that they have been understood.

At a more fundamental level, *alexithymia* is associated with autism and can limit the individual's ability to recognise, label and describe their own emotions. Consequently, when asked what fear or anxiety feels like, the person is likely to describe what they do (behaviour) or think about (cognitions) but be unable to describe, let alone name, the feeling.

- *Interests and activities unusual in their intensity, content or the amount of time they absorb, particularly if they lack a social aspect:* Their enthusiasm can lead someone to develop an expertise in a narrow, specialist field that is unusual in comparison with their other abilities and which belies an impression of general intellectual disability.
- *Unusual sensory responses:* The person may be more sensitive to a variety of stimuli, being drawn to or repelled by different sensations, which can be as diverse as certain sounds, patterns of light, repetitive movement, clothing textures, or minor anomalies such as a room's smell, a net of cracks, or the hum and flicker of a neon light. The result is that the individual, preoccupied with experiences that pass unnoticed by others, can appear distracted, daydreaming or even hallucinating. The degree of sensitivity varies but can be so intense as to produce overwhelming and incapacitating distress. A heightened awareness of certain tastes and textures may lie behind very selective eating (Eating disorders on [p30](#)). Diminished sensitivities also occur and the complicated mix can pass unnoticed unless specifically sought. However, such sensory sensitivities are not specific to autism but occur in a number of neurodevelopmental disabilities; only now is their discriminatory value being researched.
- *Inflexibility:* This can result in someone set in their ways, with fixed routines and a strong aversion, and disproportionate distress, towards change or novelty. It 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 it is something they enjoy).
- *Something unusual about a psychiatric disorder:* This could be an atypical presentation or a failure to respond to treatment.
- *A childhood onset:* While the absence of early symptoms would make a diagnosis of autism in adulthood unlikely, an individual's difficulties may remain unnoticed where there are limited social opportunities or they are well supported (as in a well-organised, 'structured' primary school) and

emerge only when they move into a more demanding setting. Alternatively, their characteristics may have been overshadowed by the presence of another disorder or a chaotic family environment.

Autism may mask or mimic a wide range of psychiatric symptoms so the mental state examination should confirm that the symptoms are what they seem. For example, alexithymia may hide anxiety or depression; hallucinations may be inferred mistakenly in someone who is detached or who suddenly becomes distracted (see unusual sensory responses on the [previous page](#)); a confident claim of many friends may be misleading as, for example, closer enquiry might reveal a concept of friendship measured by Facebook friends and work acquaintances.

The fundamental point is that there is no single characteristic pathognomonic of autism; difficulties with social understanding and non-verbal communication run through psychiatry, as do unusual sensory reactivities and obsessive symptoms. In all this, the clinician needs to find a balance between overlooking autism and seeing it all around.

The presentation of autism in adults can look very different from the stereotypes derived from early life or intellectual disability. Maturation, compensatory learning, circumstances that are relatively undemanding (compared to, say, secondary school), and co-occurring disorder can all combine to blur the picture. These, compounded by the lack of ready access to collateral and neurodevelopmental histories, combine to contribute to the under-diagnosis of autism in adulthood (Brugha et al., 2016). The diagnostic characteristics of certain groups are particularly prone to be missed or misinterpreted:

- Those embedded in a *culture which masks the features of autism*; for example, a prison, military or religious establishment characterised by its predictable routine and social hierarchy. A variation on this is the individual who blends in with a family or social group which also has autistic traits.
- Those from *another culture or where a different language is spoken*. This applies not just to those from a particular ethnic group but also to those whose lives are dominated by other disabilities, such as hearing or visual impairment or intellectual disability. In judging the significance of a symptom, the clinician will need to take into account what is the norm for that group (Dyches et al., 2004; Mandell and Novak, 2005).
- Currently autism is reported as less prevalent in *females*. While this might reflect a greater male vulnerability to neurodevelopmental disorder it also may be that its characteristics in females are less pronounced or better concealed. For example, while a male interest in Lego or trains may be obviously unusual in its quality and intensity, a female preoccupation with handbags, horses or people may accord with cultural expectations and pass unnoticed. There is the suggestion that females may be more attentive to social conventions and better at mimicking social behaviour, camouflaging their autism (Happé, 2019). There is also the suspicion that it may be misdiagnosed more frequently, for example as borderline personality disorder (emotionally unstable personality).
- There has been considerable speculation but little published evidence that autistic people differ as a group in their susceptibility to *the effects*

*of old age.* Although a lifetime of learnt adaptive mechanisms and social skills may prepare the individual to cope, innate rigidity may make it more difficult to manage the variety of change (physical, mental, social or environmental) that comes with age or frailty (Mukaetova-Ladinska and Stuart-Hamilton, 2016). Whilst the prevalence of autism in the community does not appear to change with age, the severity and impact of certain core features are likely to evolve, as well as being unmasked by the loss of supportive family members, or declining mental and physical health. At the same time, the diagnosis may be obscured by isolation, the loss of informants and the development of ill health.

## 4.2 The nature of diagnosis and assessment

### Diagnosis

Clinical diagnosis is the allocation of a series of descriptive, categorical labels that summarise whether an individual's characteristics meet diagnostic criteria. It is a classificatory, two-part process that relies on clinical evaluation and judgement to determine, first, whether the key characteristics are present (and not better explained by another condition) and, second, whether their combined intensity is sufficient to cause a disability or disorder. It is only one component of a diagnostic formulation, a summary description of the individual's predicament and its contributory factors coupled with a wider evaluation of their circumstances, strengths and skills.

### Assessment

Although diagnosis is a crucial step, it is only one component of the wider multidisciplinary (and potentially multi-agency) assessment. This broader exercise is the starting point 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 (NICE, 2012; SIGN, 2016). Tailored to the strengths, skills, needs and impairments of the individual, the range of assessments might include the following:

*Cognitive ability* – measured by various formal intellectual tests; it might identify discrepancies, for example, between verbal and performance abilities, as well as highlight the variety of specific disabilities that can accompany any neurodevelopmental disorder (such as difficulties in recognising faces or ages, appreciating time, or understanding spoken as against written language). Besides difficulties, it must include strengths, skills and talents, often overlooked because of their difficulties, to provide the rounder picture of a person that will form the basis of their management plan and allow approaches which are based on these.

*Functional ability* – besides identifying areas of ability, skill and talent that might be developed, this acknowledges 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, verbal and non-verbal), imagination, occupational and executive function. It



includes the variations in sensory awareness outlined in a sensory profile. 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.

*Co-occurring neurodevelopmental disabilities* – notably ADHD, tics and coordination disorder as well as epilepsy.

*Co-occurring psychiatric disorder* – such as anxiety, depression, bipolar disorder, obsessive-compulsive disorder, psychosis and dementia.

*Mental capacity* – the criteria for determining mental capacity and the underlying principles are well established. Subtle difficulties may arise from the characteristics of autism (see 5.1 Mental capacity and consent on [p36](#)).

*Other elements* – these include the risk of offending or of coming to harm, including drug and alcohol abuse and sexual exploitation.

*Medical problems* – these include disorders whose symptoms might have been ignored or overlooked because of the presence of autism (such as sleep problems, obesity, and cancer). Autistic people often have difficulty in drawing attention appropriately to physical symptoms, and overall are less likely than others to get healthcare (Cashin et al., 2018; Doherty et al., 2020).

## 4.3 Distinguishing co-occurring psychiatric disorder

Autism's association with psychiatric disorder, as well as other associated neurodevelopmental conditions ([p14](#)) (most notably ADHD), mean that it occurs more frequently in adult mental health services. The identification of neurodevelopmental symptomatology has become an important element in making a differential diagnosis.

### Anxiety

Although the symptoms of a wide range of anxiety disorders (including specific phobias, obsessions and compulsions, situational and social anxiety as well as general anxiety) are common in autistic individuals, they are not an intrinsic part of autism and must be treated in their own right. Here, individuals may find themselves limited by their difficulties with communication in describing a sense of apprehension, using terms such as 'feeling overwhelmed', 'stressed out,' or 'not coping,' or to describing behavioural changes such as an increase in rituals or an unusual degree of planning, preparation or avoidance. The degree of impairment may be subtle and masked by the autism, especially if that further reduces communication. Intense anxiety may result in panic, freezing, a catastrophic 'melt-down', a psychotic adjustment reaction or a more chronic form of catatonia. Sensory sensitivities frequently contribute to anxiety and these need to be identified and managed.

Sometimes it can be difficult to distinguish the unusual rigidity and routines of autism from the egodystonic symptoms of **obsessive-compulsive disorder** although, if asked directly, the autistic person is likely to decline treatment. However, an individual may present with a blend of both so that each component has to be treated in its own right (Cath et al., 2008; Ivarsson and Melin, 2008).

## Depression and suicide

Depression is frequently present in clinic populations of autistic people, not only in the individual but also in their near relatives. It is readily overlooked as some of its features are sufficiently similar to those of autism to be misattributed. It is important therefore to look for a sustained *change* in behaviour and functional ability (something that the autistic person might find easier to describe than their emotional state). For example, there may be:

- Increased withdrawal and isolation as the person becomes less interested in interacting; the increased effort required to cope with the everyday world may itself result in irritability or amplify rigidity;
- An increased sensitivity to the environment, perhaps showing as an intolerance of noise, people or places;
- Reduced speech as part of a reduced interest in, or a reduced ability to cope with, interaction (although concomitant anxiety may increase speech);
- An increase in focal interests, rumination or rituals (although a loss may be more sinister).

*The risk of suicide* by an autistic person is substantially greater than for the general population, particularly for women and in the presence of ADHD (Hirvikoski et al., 2019). Risk markers include the number of unmet support needs and the use of camouflaging, as well as the usual ones such as depression, isolation and unemployment (Cassidy et al., 2018). The presence of autism may make the usual methods of assessing the risk of suicide even more unreliable, and the ability to discuss suicidal ideas and plans dispassionately makes it difficult to judge intent. Abstract questions (such as ‘how often do you think of suicide?’, ‘how likely are you to harm yourself in the future?’) can result in unexpected and logical responses (for example, calculating all possible causes of self-harm over the next forty years) suggesting an alarmingly high risk.

Questions need to be well-defined and straightforward and, besides the blunt ‘do you want to/are you going to/when,’ might include:

- ‘How many times did you think of harming yourself today?’
- ‘How long did you think about it when you got the thoughts?’
- ‘Do you think these thoughts will be less or more over the next week?’
- ‘When you get the thoughts how do you respond to them?’

There is a fuller account of the adaptations required in an interview on [p33](#).

## Post-traumatic stress disorder (PTSD)

A difficult, stressful early life is so frequent as to appear characteristic of autism ([p14](#)). Some autistic people describe symptoms associated with PTSD (such as involuntary rumination) with more vigour and clarity than normal and these may blur into relived past events. For example, a vivid rumination about a past event may be misidentified as a PTSD flashback and attributed to past adversity, misdiagnosis or mismanagement, but may well respond to supportive psychological therapies.

At the same time, autism does not preclude PTSD, which should be treated with the appropriate therapies although these may need adaptation.

## Burnout

This describes a state of exhaustion, associated with functional and cognitive deterioration and an increase in autism symptomatology, as a consequence of coping with social interaction (including masking) and the sensory environment. It may be a short-lived state (as at the end of a working day), relieved by a relatively brief withdrawal from the stress. However, longer and more severe stress can produce a more sustained state (which entails some form of innate change) which has to wait on its natural remission. It overlaps symptomatically with anxiety and depression, and there may be a heightened risk of suicide.

Its anecdotal basis and the lack of systematic research mean that burnout does not have the status of a formal syndrome or disorder. Nevertheless, the concept captures the need to consider the effect of adjusting somebody's setting, support, and style of life before assuming their malaise to be a recognised psychiatric disorder.

## Schizophrenia

As noted on page [14](#), there are times when the clinician may have difficulty in distinguishing autism from schizophrenia. Given that autism has a childhood onset and schizophrenia starts later, the developmental history of early childhood (if available) should help to disentangle the two (Larson et al., 2017), as well as an objective examination of the symptomatology (Table 1).

Table 1. A comparison of the features of autism and schizophrenia.

	Autism	Schizophrenia
<b>Onset</b>	Early childhood (but symptoms may remain unrecognised until adolescence or even adulthood)	Later adolescence/adulthood
<b>Abnormal experiences</b>		
<b>Hallucinations</b>	The response to subtle stimuli (p22) or the interaction with imaginary friends can be mistaken for a response to hallucinations; fleeting visual illusions may be difficult to distinguish from hallucinations	Some forms of hallucination are considered pathognomonic of schizophrenia
<b>Passivity Experiences</b>	Thought insertion and similar phenomena are not part of core autism	Some forms of passivity phenomena are thought pathognomonic of schizophrenia
<b>Hyper/hypo-sensitivities and unusual responses to sensory stimuli</b>	Commonly reported and clinically apparent, these symptoms are included in the RRB component of the diagnostic criteria for autism	Rarely clinically apparent
<b>Delusions</b>	Thinking is black-and-white, literal and rigid and, coupled with difficulty in explaining underlying reasons, may appear delusional; paranoid concerns about the public can occur as overvalued ideas and, at times of stress, may become more firmly held	Some forms of delusion are considered pathognomonic of schizophrenia
<b>Interaction</b>		
<b>Speech</b>	Commonly concrete, overinclusive, tangential, or with cluttering, speech may mimic psychotic or hypomanic thought disorder although, if teased out, it is logically connected	Sometimes concrete, incoherent or irrelevant speech is part of the diagnostic criteria
	Poverty of speech may occur in both conditions	
<b>Social interaction</b>	Usually little innate curiosity about the personal lives of others; impaired unthinking, <i>intuitive</i> understanding perception and emotions of others; impaired <i>reciprocal</i> social conversation; however, effective masking may obscure this with behaviour that is learned or deduced	Often interested in others but paranoid ideas may lead to social withdrawal; a relatively reasonable understanding of emotions

	Autism	Schizophrenia
<b>Non-verbal communication</b>	A lack of gesture, of expressive eye contact, or of facial expression may be obvious unless the person has learned compensatory strategies; when present, this limitation of expression may be attributed erroneously to medication; although comprehension is often impaired, this is less readily detected	Expressiveness may be reduced both by schizophrenia and by medication
<b>Friends</b>	Difficulties making and maintaining friendships; responsiveness in intimate relationships can be more limited	Variable but friendships are often emotionally committed
<b>Rigid or repetitive behaviour</b>		
<b>Resistance to change</b>	A general desire for sameness/routine/predictability (with an intolerance of uncertainty) is common	Where it occurs, it is usually the result of institutionalisation
<b>Intense interests and preoccupations</b>	Specific, isolated, restricted, intense enthusiasms are common	Intense interests rare unless they are the subject of delusion
<b>OCD</b>	OCD-like behaviour common and reflects an (egosyntonic) desire for organization and routine as well as presenting as focal interests; however, egodystonic symptoms can also occur and both are increased by anxiety	OCD-like symptoms are common; some may be linked to delusions
<b>Motor behaviour</b>	Characteristic motor mannerisms (e.g. finger twiddling, hand flapping); repetitive stereotypies are common	Mannerisms can occur, especially in untreated chronic schizophrenia, and in those who are socially isolated or over medicated
<b>Other features</b>		
<b>Co-occurring disorders</b>	Anxiety and mood disorders common in both	
<b>Response to medication</b>	Antipsychotic medication does not improve core skills but anxiolytic medication can reduce disability by dampening anxiety; adverse and idiosyncratic effects are often reported	Antipsychotic medication can improve core skills by improving psychotic features

Sensory anomalies, resistance to change, or restrictive and repetitive behaviour such as motor mannerisms, rituals, severe routines or intense interests should lead the clinician to consider autism given their infrequency in schizophrenia.

Many of the psychological and environmental approaches for schizophrenia reduce distress and will benefit autism, reducing but not eliminating its features. Therefore, the persistence of symptoms should raise the possibility of concurrent autism which, if both conditions are present, will need to be included in the rehabilitation plan.

## Eating disorders

Autism is associated with two broad categories of eating disorder:

- **Avoidant/restrictive food intake disorder (ARFID).** Autism can bring sensory sensitivities, a resistance to any dietary change or an intense interest in a specific diet or in specific dietary components, as well as too literal a response to dietary advice. Any of these can result in a very restricted, bizarre diet and a pattern of eating which is difficult to change and potentially dangerous, particularly when combined with a preoccupation with fitness and exercise. This selective appetite is distinct from anorexia nervosa and body dysmorphic disorder.
- **Anorexia nervosa.** This is associated with autism although the relationship is complicated. There is the difficulty in identifying autism in adult women in the presence of co-occurring psychiatric disorder. Second, being underweight may, of itself, lead to the development of reversible autistic symptomatology or may simply unmask previously unrecognised autism (Westwood et al., 2017).

As in the other conditions, a good developmental history (from an informant) may help to establish the nature of the eating disorder allowing the therapist to tailor their approach.

## Extreme/pathological demand avoidance (PDA)

Although not recognised in the international classification systems (ICD and DSM), this controversial label has been adopted by some in the UK and mainland Europe. Confusion arises as demand avoidance itself is a common symptom.

PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:

- avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
- anxiety when demands cannot be avoided,
- attempts to control situations,
- impulsivity as well as sudden and extreme changes of mood.

There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right (Green et al., 2018).

Individuals identifying with PDA, and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities. In the short term there might need to be a greater emphasis on reducing confrontation until a wider range of management strategies is in place.

## 4.4 The purpose of diagnosis

For most, diagnosis is a further step in the development of their identity, with a better understanding of themselves and their relationships with others. The diagnostic label can help to explain, both to the autistic person and to others, their characteristics and the reason they might require support and adjustments. A diagnostic formulation can inform care planning and lead to more appropriate support, accommodation, education and occupation, all with the overall aim of a more successful life in the wider community. It may be the springboard to relevant information, specialist support groups, and resources (including financial benefits). It might avert a crisis and allow diversion from hospital, court or prison. In short, diagnosis has many functions and its nature, and the clinician's threshold, will be coloured by its immediate purpose:

- *Clinical* – here the diagnosis is part of the summary of an individual's profile of skills, needs and difficulties, the diagnostic formulation, that is the starting point for a plan of management.
- *Research* – where the defining criteria will depend on the nature and aims of the study. Thus, an individual may be excluded because their profile or 'score' does not meet the study's inclusion criteria, there is insufficient information, or there is simply doubt. Exclusion does not necessarily mean that the individual does not meet the criteria for a clinical diagnosis of autism.
- *Administrative* – here the diagnosis may facilitate a specific outcome or disposal, or entry to particular services and resources, particularly where these are determined by label rather than need.

There is no definitive biomarker and therefore no laboratory test for autism. Diagnosis is a clinical judgement, initially provisional, that clarifies with time as circumstances change and more information is gathered. Although the diagnostic decision is binary ('is this autism or not'), the formulation and its subsequent plan of management is anything but, as they have to be tailored to the individual and their place on a wide range of potential disability, co-occurring disorder, and circumstances. At one extreme there are people 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 are some who need extensive support and care. In between are those who might go onto

a pathway of stepped care which, at different times, may shift from ‘watch and wait’ through to substantial multidisciplinary/multi-agency involvement. Finally, there are those for whom the process did not diagnose autism (the majority in some centres) who will need guidance and, where necessary, management or re-referral.

## 4.5 The process of diagnosis

People come to diagnosis by varied routes. Some may not be autistic but, drawing on a variety of sources that include the internet with its self-rating scales, have found that autism might be a way of understanding themselves and come seeking confirmation. Others, with a close relative with autism, have come to recognise similar traits in themselves. They (or their family/carers) may know a great deal about autism and have clear expectations of what a diagnosis should bring. Some will be coming, perhaps reluctantly, at the urging of their family, friends or work colleagues. Then there will be those, diagnosed in childhood, for whom a change of circumstances or presentation has made them want to have their diagnosis reviewed.

Assuming the individual has mental capacity, it is essential that they consent to the diagnostic process and its implications. Their wishes may be overlooked by family and/or carers, particularly where there has been a longstanding dependency, who may not appreciate that the individual has the competence to withhold consent, both to diagnosis and to the sharing of information (Royal College of Psychiatrists, 2017). The purpose, potential benefit and risks of diagnosis must be explored early as it will shape the referral process.

It cannot be assumed that most autistic people will be 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, and the more complex demands of secondary schooling, to bring out the characteristics sufficiently for the syndrome to be recognised. Even then, much depends on their local services, for the perception of autism is an evolving one and the diagnostic threshold varies over different services and at different times.

Many will reach adulthood undiagnosed, their autism only coming to light with adversity. This may take a variety of forms, including the environmental pressures of work or independent living, redundancy/retirement, a change in social or marital relationships, a loss of support following bereavement, entanglement with the law, the onset of co-occurring psychiatric disorder, physical illness, or frailty with a deterioration in physical or cognitive ability. A move to an unfamiliar setting or routine, for example on going into hospital or care, can result in a catastrophic decompensation, with the emergence of previously unnoticed characteristics. Then there are those for whom the significance of a childhood diagnosis may have been lost as they move between services.

Wherever possible, the clinician should go beyond their diagnostic interview with the individual to acquire information from informants about:

- the individual’s current presentation and adaptive functioning
- their neurodevelopmental history
- previous assessments (including early health and education records).



In the end, the quality of the diagnosis will depend on the extent of the clinician's experience and knowledge and their rigour in applying standard criteria. The potential for overdiagnosis, underdiagnosis and confusion with co-occurring disorder means that the clinician requires:

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

Time is a factor and, while there is an appeal about the brevity of a diagnostic process that focuses only on the current features, it is important to remember that its conclusions will have far-reaching consequences. Subtle or complex cases require more time, such that a definitive interview, enough to refute (as well as confirm) a diagnosis and to identify co-occurring neurodevelopmental and psychiatric conditions, can take several hours and involve more than one professional. It is not to be undertaken lightly or without sufficient resources and a clearly defined purpose ([p47](#)).

**The interview** needs to be adapted to the underlying characteristics of an autistic person; the clinician might:

- Reduce anxiety; here the clinician should be guided by the individual as well as by their friends and carers. As far as possible the autistic person should know what to expect: where an appointment is, at what time and in what kind of venue, with whom, and its purpose, duration and format. In short, the interview should be as structured and predictable as possible as any uncertainty may result in a counterproductive degree of anxiety. For example, rather than waiting on a delayed clinic, it may be better to suggest that they leave the area to return at a set time.
- Ensure that the environment is quiet, distraction-free, calm and comfortable for that individual. It is worth asking in advance whether they have any specific sensory needs.
- Encourage the presence of a friend or advocate who can help the individual to understand and, afterwards, to digest the content of the interview.
- Use straightforward, unambiguous, simple language and short sentences and avoid constructs that might be misinterpreted, such as figurative speech, irony, metaphor and colloquialism. 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') is often accompanied by a tendency to take what is said literally. Any suspicion of misinterpretation should be reviewed immediately.
- Allow the person enough thinking time to process what has been said and check that a point has been understood before moving on. Verbal

fluency may give a misleading impression of comprehension. Should the clinician respond too soon or with too much, it may overload the individual's auditory processing so that they are unable to grasp the meaning, even though they may be able to repeat back what has been said – individuals often echo something as they try to understand it, giving a false impression of comprehension.

- Allow the person enough time to overcome their initial difficulty of putting their thoughts into words (an aspect of a catatonic difficulty in initiating voluntary action: see Catatonia on [p15](#)).
- Give a limited number of choices at a time, each with a clear effect.
- Use diagrams and visual text to help comprehension, and summarise the main points of an interview in a confirmatory letter.
- Adopt a more concrete and structured approach, focusing on practical matters, actual behaviour, and specific problems rather than abstract concepts.
- Be wary of relying on the autistic person's memory of the emotional content of previous sessions or of their ability to put a name to emotions, whether their own or those of others.
- Be aware that autistic individuals may report their inner experience in unusual ways that should not be dismissed or immediately presumed to be psychotic phenomena.
- Show a readiness to explore the values of the individual and to work with them, whilst recognising that they may be idiosyncratic.

## 4.6 Tests for autism

A variety of instruments are available, ranging from screening questionnaires through interview frameworks to structured interview schedules, the categories reflecting their different purposes (Appendix 1). The interviews help clinicians collect the appropriate information in a format that lets them match it against their agreed criteria as well as giving them a framework to organise their thoughts. They do not make a diagnosis nor, more importantly, do they exclude it. They are a means by which different clinicians in different settings can achieve a recognised, consistent threshold as well as adapt to changing criteria and practice.

A test's underlying construct may be refined by an algorithm which operationalises the diagnostic categories and gives a better picture of their contributing components. However, algorithms are a research tool and their mechanical simplicity is misleading in a clinical context where diagnosis is ultimately a matter for the clinician's judgement.

A number of questionnaires have been proposed to help in the selection of individuals for further assessment, but their clinical effectiveness is questionable and, particularly in mental health settings, the use of a single structured questionnaire is unlikely to be sufficiently reliable either to identify adults who are not autistic or to differentiate autism from mental health conditions. (Wigham et al., 2018). It is important to appreciate that the characteristics of an instrument (such as its sensitivity, specificity and misclassification rate) will depend on the population it is being used on; whether, for example, it is a group attending a diagnostic clinic or a psychiatric clinic, or one drawn from the general population.

The College has developed a [Diagnostic Interview Guide for the Assessment of Adults with ASD](#) to be used in conjunction with the standard psychiatric interview, and provides training in its use. Other instruments have been developed and Appendix 1 provides a summary of those that clinicians and their patients are likely to encounter.

# Chapter 5: Legal aspects of psychiatry

As experts, psychiatrists provide information to the legal system in written reports or verbal evidence that would not otherwise be known. If this is to be considered credible and given due weight, then the psychiatrist must take note of the relevant College guidance (Royal College of Psychiatrists, 2015).

## 5.1 Mental capacity and consent

While autism may bring a particularly objective approach to decision making, it is associated with several issues which can complicate the assessment of mental capacity and thereby the validity of an individual's consent to treatment:

- Difficulties with comprehension, ranging from a tendency to interpret language literally to problems with auditory processing, which may be masked by superficially 'mature' speech
- Difficulties with attention and concentration: these can hinder understanding information, particularly if made worse by physical discomfort, sensory distraction or anxiety
- Rigid perceptions of how the world works (or should work), or of the cause and consequence of particular events: a strong and fixed belief can so bias an individual that it becomes difficult for them to judge the authority and motivation of information and informants; examples are the beliefs that if it is published on the internet, it must be true or that anything said by established authority (police, politicians or psychiatrists) is false
- Problems coping with change or uncertainty which may result in an overriding aversion to anything new, making it difficult for an individual to weigh up information and judge what is relevant
- Problems in understanding the motivations of others, which may affect understanding the risks of contact with them
- A difficulty in weighing the choices: this may be a consequence of the autism itself (e.g. difficulty coping with too many choices or hypothetical choices) or may result from a co-occurring condition such as anxiety or depression (Luke et al., 2012).

In addition to an appropriate interview style (p33), various measures may help an autistic person in their decision-making; for example:

- Limiting a decision to a choice between just two or three options and, if possible, making these as concrete as possible (for example, by seeing them or trying them out before discussing which to choose)
- Providing information in written form, using diagrams as well as text; for example, a list of pros and cons to promote discussion on what is important to them, a visual scale to express how much weight they place on it, and a road map to work out its implications
- Avoiding a rushed decision; this is essential and, depending on its importance, it may be useful and necessary to repeat the exercise on another day
- Making it clear that, if a choice is made with capacity, it will be accepted and worked with even if it appears unwise.

## 5.2 The ability to bear witness

Autistic people, as much as anyone else, have the right to give an account, whether as a defendant or as a witness, and to be believed. However, any assessment should bear in mind a number of potential factors which may affect their ability to give an accurate and reliable account of an event (i.e. to be a reliable witness) (Maras and Bowler, 2012b):

- An unusual perception of the significance of events, whether as observer or performer, that increases the 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 relationship between events that occurred on the previous day, week or year
- Difficulty in distinguishing reality from fiction (e.g. remembering events seen in films or on television as factual) which may extend to a confusion between their own actions and those of others
- Difficulty with the prescribed structure of official interviews, whether in the police station or court: the unfamiliar and formal surroundings and circumstances are likely to increase any innate disability in communication, both verbal and non-verbal. It is important to remember that an autistic person may find it difficult to understand the interviewer, particularly if the style is not adapted to their needs (p33). The interviewer might also be misled by responses given with an inappropriate or limited vocal tone or facial expression (particularly smiling or laughter, not unusual as reflex responses to anxiety). Delays in processing speech, selective mutism or simple stage-fright are easily misinterpreted as wilful (p22)

- 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
- It has been proposed that, while an autistic person is no more suggestible than anyone else, they may be more compliant. However, this simply may reflect their level of anxiety while being interviewed (Maras and Bowler, 2012a).

At the same time, an unusual presentation or obvious difficulties with communication can lead to an underestimate of an autistic person's ability to bear witness and a failure to appreciate strengths that might be present, such as an unusual perception of detail or a photographic memory.

Some will qualify as a *vulnerable adult* and should have the protection of the presence of an *appropriate adult*, a need that may go unrecognised if not routinely considered. Similarly, a defendant's impairments due to autism may be relevant when considering fitness to plead. A good intellectual awareness of right and wrong, and of the nature of the court and its proceedings, can be insufficient when legal issues become complex (Barry-Walsh and Mullen, 2004; Freckelton, 2012). Defendants can be compromised further if they are unable 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 autistic adults 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, using means such as those listed under decision-making (p37) and interviewing (p33). 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 and, for some, using a video link. The judiciary has become better informed about the needs of autistic people 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, 2017; National Autistic Society Northern Ireland and Department of Justice, 2014),

## 5.3 Offending behaviour

Most autistic individuals respect order, are keen to avoid trouble and do not offend (p16). Several factors may offset this and result in a vulnerable individual who is prone to getting into trouble:

- A naive misinterpretation of social relationships which can 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 may be misinterpreted as the stronger emotion of love.

- A misinterpretation of rules which 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 model the behaviour with little understanding that it should not be translated into real life.
- Difficulty in reading social signals and cues. A specific difficulty, which is unusual and readily overlooked, is the inability to gauge the age of others. This leaves the individual open to an inadvertent sexual approach to somebody underage, something that is made more likely if their social ineptness has led them to become part of a younger peer group.
- An unusual passivity that leaves the individual vulnerable to being influenced, exploited or radicalised by others.
- Impulsivity, occasionally violent, that may be a component of co-occurring ADHD, a state of anxiety turning into panic or a confusing blend of both. The result can be a disproportionate emotional response (e.g. a 'melt-down') that is perceived as threatening.
- A limited awareness of the outcome of their actions, its seriousness or its 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 (with blame being ascribed to someone else) and an inability to see their behaviour as others see it.
- Overriding preoccupations or special interests, especially if coupled with limited self-awareness, which can lead to offences such as stalking, compulsive theft, computer hacking, or fraudulent trading. Occasionally the preoccupation with justice can itself become a source of vexatious complaint or harassment. Admonition may increase anxiety and result in ruminative thinking about the behaviour, increasing the likelihood of its occurrence.
- Misjudging the nature of an interview or other social interaction, which 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 a lack of insight can lead to socially inappropriate disclosure.
- Someone who fails to appreciate any need to change or who finds change inordinately difficult can become stuck in a risky pattern

of behaviour: a problem that may be made worse by co-occurring dysphoria, anxiety or any other mental state that reduces flexible thinking

- A predisposition to provocative behaviour, apparently malicious and inexplicable, but possibly a way of testing out social and emotional responses by someone who has a particular difficulty with non-verbal comprehension.

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

## 5.4 Disposal in the criminal justice system

Sentencing (on conviction) or disposal (if unfit to plead or insane) will depend on:

- i. whether there is any mandatory sentence (for example, murder, where life imprisonment is a mandatory sentence)
- ii. whether hospital assessment and treatment is necessary and
- iii. whether any form of community sentence is available.

The minimum term of imprisonment will depend on aggravating and mitigating factors. Whilst mental disorders are, in general, likely to be considered as a mitigating factor, features of autism may be misattributed as aggravating factors; for example, autism being perceived as intrinsically dangerous or social and communication difficulties being interpreted as callousness or lack of remorse.

Hospital treatment may be appropriate for some more serious offences. That the offending behaviour is related to the autism does not necessarily mean that there is a treatment and that it will be helpful; often it can be judged only by seeing the individual's response. The courts will expect a genuine offer of treatment that may help prevent further offending, not a guarantee of its effectiveness. Any hospitalisation should be focussed on rehabilitation that eventually leads back to the community, rather than slipping into an indeterminate period of detention.

An alternative to the choice of either prison or hospital is a prison sentence that includes a hospital direction: a 'hybrid' sentence where any immediate period of hospital treatment will – if the treatment is completed – be followed by a return to prison to complete the sentence with a more predictable length of detention.

Some individuals simply require consistent supervision in the community to prevent a drift back to the circumstances that led to their offence. A requirement for mental health treatment can be added to community and suspended sentences, if this is agreed to by both the autistic individual and the clinician who is to provide the treatment.



There are some autistic individuals 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 are 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 enough to produce a risk of self-harm, suicide or a psychotic state. Specialisation in the care of autistic prisoners is being encouraged.

# Chapter 6: Management

## 6.1 The management of autism

The management of autism itself (as distinct from that of co-occurring disorder) is primarily about the provision of the education, training and social support/care required to live independently and to function in the everyday world (Balfe and Tantam, 2010). Unfortunately, these resources are patchy and many people remain very dependent on their families.

## 6.2 Psychiatric management

Psychiatric input is largely about the treatment of the co-occurrent disorders that frequently accompany autism. These might be expected to be managed by standard adult services, using standard treatments albeit with appropriate adjustments to accommodate the autism. At the same time, the long-term nature of their difficulties is ill suited to the recovery model of care ([p46](#)).

The presenting difficulties of an autistic individual, including their autistic characteristics, will be improved by anything that reduces their anxiety or increases their physical comfort and sense of well-being. This may come from better communication and social understanding, an improved environment (more familiar and predictable with reduced sensory stimuli), the relief of physical malaise (for example, the relief of pain or discomfort as well as the better management of epilepsy, sleep and medication) and the treatment of co-occurring psychiatric disorder.

Many interventions have been promoted for different aspects of autism, regardless of evidence of their limited effectiveness or their potential for harm and financial exploitation. A tangible treatment can have a powerful placebo effect both directly on the autistic individual and indirectly through its effect on the attitude and behaviour of the family and carers (Sandler, 2005; Sandler and Bodfish, 2000). Besides official guidelines, Research Autism (supported by the National Autistic Society) provides a regularly updated online summary of treatments, their efficacy and evidential underpinning ([www.researchautism.net/autism-interventions/alphabetic-list-interventions](http://www.researchautism.net/autism-interventions/alphabetic-list-interventions)).

### Medication

Guidelines have been published by the British Association for Psychopharmacology (Howes et al., 2018) and NICE (NICE, 2012). At present, there is no place for the routine use of medication in the management of *the core features of autism* for, while some symptoms may improve, the risk of adverse effects means that it should be considered only on a case-by-case basis. Even then, medication should be only one component

of a multimodal approach that can include psychological therapies, education, and environmental change.

Medication is used for *co-occurring conditions* as with non-autistic people. However, it appears that autism might be a marker for an unpredictable and individual response to psychotropic drugs: sensitivity may be increased or decreased and idiosyncratic and adverse effects are more frequent. Consequently, drugs should be introduced at a low dose, increased cautiously and with careful monitoring, and reviewed regularly.

Three circumstances may require medication:

- ADHD: a frequently co-occurring condition ([p14](#)), should be treated in its own right.
- Psychosis: emotional stress occasionally leads to a brief reactive psychosis, difficult to distinguish from schizophrenia. Although treatment of the latter should not be delayed, it can be difficult to disentangle the characteristics of autism from those of the psychosis once established on antipsychotics, affecting early weaning.
- Epilepsy: the association of autism with epilepsy has led to trials of various forms of anti-epileptic treatment to improve the characteristics of autism (Besag, 2009) and, while autistic features improve with seizure control, the results are equivocal in the absence of clear evidence of seizures (Tuchman et al., 2010). The arguments for the use of antiepileptics are similar to those aired in the debate on the use of surgery for ill-defined seizure activity (Palac et al., 2002).

## Psychological treatments

*Cognitive-behavioural therapy* and the need for its adaptation to the autistic person has been reviewed by NICE (National Institute for Health and Clinical Excellence, 2012). Less attention has been given to other types of psychotherapy and counselling, presumably because of the lack of systematic trials of these interventions with autistic people. However, lack of evidence is not evidence of ineffectiveness and autistic individuals should have access (albeit with reasonable adaptations) to the types of treatment for anxiety and depression that are recognised as an integral part of mental healthcare for the wider population.

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. Therapists need to allow for the possible variations in cognitive style, communication, skills, narrative and value system that might come with autism and adjust their interview accordingly ([p33](#)). Therapies applied without awareness of the autism can be harmful or, at the least, ineffective.

The frequency of bullying, victimisation, and abuse, contributing to a complicated and turbulent life (Balfe and Tantam, 2010), make *trauma informed care* particularly relevant to this population. The emphasis is on the provision of a safe and consistent

setting within which the person can develop long-term relationships, as well as enabling their perspective to be heard and understood as they share their earlier experiences. Nevertheless, the communication difficulties associated with autism are an opportunity for misunderstanding which, coupled with the mandatory requirement to report and investigate abuse, might lead to a trauma-informed approach slipping into one that is trauma-centred. The latter, with its focus on active exploration and interpretation, is an area to be approached with caution.

The families of many autistic people have come to be protective and act as their spokespersons, advocates or 'next friends.' As discussed earlier ([p32](#)) the boundaries of confidentiality may be blurred and the individual's mental capacity underestimated. The therapist therefore must be prepared to work out with their patient how best to engage before discussing their plans more widely, a process which must respect the patient's confidentiality but also recognise its statutory limits (Royal College of Psychiatrists, 2017). Changing circumstances mean that this relationship must be reviewed regularly over time.

# Chapter 7: Services

## 7.1 Services other than health

Many individuals, identified as autistic, require consistent help over a relatively long period of time from a wide variety of local agencies and disciplines. Planning needs to go beyond the more obvious resources of health, education and social services and look to the wider variety of agencies available which, for example, might include:

- peer group support through the internet and the variety of voluntary groups both national (such as the National Autistic Society (NAS), Scottish Autism, Autism Cymru, Autism NI) and others that are more local
- support and residential services: these include a range of options, from registered care through to independent supported living (although a provider's claims of specialism/familiarity with autism should not be taken at face value). Support might include helping individuals to manage their finances, advocacy for people pressured by housing and employment problems (such as harassment by neighbours or inappropriate employment) and dealing with the criminal justice system; it can extend to address the needs of carers
- educational services, including both higher and further education; increasingly, universities, recognising the need for social as well as academic support, have introduced disability coordinators and mentors; Further Education colleges have the potential to include courses/modules which focus on specific areas of daily living and independence skills, 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; these programmes put as much emphasis on avoiding arousal as on responding to it
  - independent living skills in all the areas necessary to everyday life (e.g. shopping, budgeting, housekeeping, laundry and personal hygiene)
  - preparation for work (e.g. how to apply for a job, interview skills, behaviour at work and coping with colleagues)
  - accessing leisure activities.
- occupational support – disability employment advisors (based in Jobcentres) are becoming more familiar with autism and some independent agencies have established services to support individuals and

employers in work settings (e.g. Prospects, a service established in several cities by the NAS).

Services need to take account of the individual needs and aspirations of the autistic individual and their family. The approach should be person-centred, something that takes on meaning where the autistic person's aims are rather different from those around them, adapted to the individual's circumstances, culture and belief and usually involving their families and carers. Families from ethnic minorities or other sub-cultures (e.g. the deaf community) may have linguistic or communication barriers, reinforced by mistrust and misunderstanding, as well as a different understanding of the need for a specialised programme. All of these can affect the adult's access to, and interaction with, a particular service and their choice of approach (Dyches et al., 2001; Mir et al., 2001; O'Hara, 2003).

Factors such as these and the varied ages, abilities and circumstances of autistic individuals make for a wide remit which can involve any of the psychiatric specialties, as well as drawing on the services and expertise of other disciplines and agencies. This can create a daunting bureaucratic thicket and the need for a guide. A frequent proposal is a key worker but availability is limited. A successful response to this challenge is the One Stop Shop project in Scotland, a community facility that draws on volunteers to provide information, advice and signposting, as well as support to individuals both before and after diagnosis.

## 7.2 Psychiatric services in the community

Access to services presents a hurdle to many autistic people, particularly if they live an isolated life. Unfamiliarity, unpredictability or difficulties with communication (e.g. in using a telephone) can make arranging an appointment a daunting experience whether it is in primary care, with a specialist team, or a hospital clinic. Access can be helped by staff and public education, the use of online booking and communication, and a *Hospital Passport* (a document carried by the autistic person which sets out their characteristics and needs) and appropriate adaptations to the interview ([p33](#)).

While the generic NHS 'recovery' model is based on circumscribed episodes of treatment, much psychiatric disorder runs a course involving the continuity of regular review over a longer term, requiring a service model appropriate to those with chronic, fluctuating difficulties. For many autistic people, a reluctance to seek help, aggravated by habitual isolation and the absence of anyone to consult, lends itself to a drift into difficulties with physical and mental health and everyday living. Ill-served by a system based on episodes of care, they need the ready contact that comes with long-term oversight or support: some form of continuity is important rather than a reliance on self-referral to their GP or social worker.

Services have evolved differently across the UK. Provision in England is defined by commissioning groups and care pathways which are beginning to consider post-diagnostic support and access to the wider network of care as well as diagnosis. In adulthood, the diagnosis of autism will depend on the purpose (clinical / research / administrative), the referral route, and the complexity of presentation (whether subtle,

atypical, or complicated by the presence of co-occurrent disorder). Some people will be identified by a community mental health team or in a psychiatric clinic, while others will be referred to a Specialist Autism Team (SAT) or its equivalent. This should lead on to a wider, multidisciplinary assessment of the individual's strengths and weaknesses and to a management plan.

**Specialist autism teams** (SATs) are being established, often complementing or combined with an ADHD team to provide a more comprehensive neurodevelopmental service. Varying in composition, their core membership usually includes psychology and nursing but may extend to psychiatry, social work, speech and language therapists and occupational therapists, to provide the comprehensive assessment necessary to treat complex problems. As yet, there is no national network nor a strategic direction as to how these specialist teams might work together with the other community services.

Local agreement needs to define these relationships, including the community learning disability team as well as the adult mental health team. Although the former are usually familiar with autism, they may not be commissioned to work with people whose cognitive abilities (e.g. as measured by the Wechsler Adult Intelligence Scale) lie within or above the normal range, even though their functional abilities (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 recommendations of Valuing People (Department of Health, 2001).

The risk remains that some autistic adults will continue to fall between the different mental healthcare contracts despite their statutory entitlement to access psychiatric services. Therefore it is important that there is explicit provision in each locality, extending beyond the diagnostic process, to provide services for the treatment of their co-occurring mental and physical disorders and the coherent involvement of the wide range of agencies and services that can benefit the individual.

The growth of **specialist services**, many in the independent sector, often ostensibly for the social care and education of autistic people, makes for a rich source of knowledge of the effects of autism and the resultant needs. At the same time, the presence of these services encourages the out-of-area placement of those individuals whose high levels of need and disturbance have led to specific additional funding. Such placements can be difficult to monitor, a significant financial burden for their sponsoring health economy, and an additional drain on local services, as well as further dislocating the person from all that is familiar to them: their community, family and acquaintances. The result can be an isolated placement where it is difficult to ensure that the staff have proper managerial supervision and clinical support, a recipe which produced the abuse of Winterbourne View (Flynn, 2012).

Greater success has come from planning tailored community placements, by bringing together specialist autism providers (whose competence is confirmed by their track record) and local teams, including those who will be called on to respond on a day-to-day basis (whether from adult mental health, rehabilitation, 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 community staff. After discharge, individuals need enough time and opportunity to gain the skills needed for community life, a process that may be slow but must be at a pace geared

to that person. Failure is often the start of a damaging and expensive cycle of repeated placement breakdown.

**The role of the psychiatrist:** 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 ([p58](#)):

- Diagnosis – particularly where the presentation is complex or involves a co-occurring disorder, for it is essential not just to recognise autism but also to be able to discount it, which requires 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 enough 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 co-occurring disorder or unresponsive to standard approaches
- The assessment of certain forms of risk
- The recognition and management of co-occurring 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).

Psychiatrists should work closely with other agencies and understand their key roles within a jointly agreed local care pathway. Examples of such approaches, that come from other areas of psychiatry, are the close collaborative working of old age psychiatry with social care for dementia, general adult psychiatry with primary care in the management of depression, and child psychiatry with education and the local authority for young people with special needs.

**The general practitioner (GP)**, who should have a comprehensive overview of an autistic individual's circumstances, has a particular 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.

**The psychiatrist's communications** about diagnosis and treatment should be clear and unambiguous, particularly where the GP is being asked to take on prescribing or organise treatment. They might consider a brief letter, setting out what was important from the consultation with a summary list of diagnoses, current medication and recommendations (including its purpose, benefits and drawbacks) alongside a longer letter/report, perhaps addressed to the patient.



## 7.3 Psychiatric treatment units

Autism itself neither requires psychiatric treatment nor warrants admission, but treatment may be needed for co-occurring disorder. There is a greater readiness to manage this in the community, largely helped by the increased availability of specialist community placements. Nevertheless, there will be times when hospital admission is required and then the facilities need to be sufficiently autism-friendly to avoid undermining the treatment.

Whether as a day- or an in-patient, the autistic person can find admission more daunting than most; uncertainty, unfamiliarity, a loss of control, the challenge of coping with strangers and sensory difficulties all contribute. At present, few psychiatric units provide either the setting or the levels of staff necessary to prevent conflict and to protect an autistic individual from bullying and harassment. Without autism training, it is difficult for staff to understand characteristics such as sensory sensitivity, communication overload or the need for rituals and strict routines, let alone to accommodate them. In addition, besides lacking appropriate psychoeducational programmes, many units use cognitive or group approaches that, without adaptation, can cause people to fail or to refuse therapy for reasons that they may not be able to put into words.

**The autism-friendly psychiatric unit:** 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 (staff, buildings and programmes) should be structured, predictable and calm. Stimuli should be of low intensity and the overall aim to reduce emotional arousal. There should be regular routines, consistent responses, the use of clear (and visual) communication, and a restricted number of people (staff and 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 specific sensitivities and perspectives of each autistic individual in their care. This means that the unit needs to be attuned to the individual patients rather than work to some generic, nonspecific concept about autism. A high priority should be given to the relationships, both social and professional, with others, outside the staff team, involved with the individual. There needs to be an emphasis on regular staff training in autism and, to avoid stagnation, on the development of relationships with other specialist autism services and on input from autistic people. In all of this, safeguarding must be a central thread, keeping the patient safe from abuse and exploitation, whether by staff or other patients, with an emphasis on the relationship and communication with the patient.

**The specialist autism unit:** There are some individuals for whom even good quality, autism-friendly provision will be insufficient. The intensity of their autism, with its associated perceptual sensitivity, emotional fragility, and need for predictability, means they requires an unusual degree of structure, a low-stimulus setting, autism-specific programmes and highly skilled, specialist staff. In addition to psychiatric treatment, they will need the therapeutic and educational programmes designed to minimise the disabilities of their autism. Although several hospitals declare their interest in providing specialistic care for autistic adults, very few have the dedicated facilities or necessary expertise. Individuals can find themselves on units where the ethos, training and experience is more appropriate to people who have a general intellectual disability or who simply require an unusual degree of security.

**Extended hospital admission:** Very few people will be sufficiently violent or dangerous to warrant an extended hospital stay. For many, however, it is not unusual for their admission to become extended when it is realised that they are going to require a specialist community placement and substantial resources. For them, admission has a fly-paper quality, trapping them until an exit route can be established and funded.

While *Transforming Care* was expected to change this, the difficulty of developing new resources in the community and the reduction in the number of NHS hospital beds have led to a compensatory growth in the private sector for those that require extended hospital placement. Where behaviour is sufficiently violent to require recurrent restraint, seclusion, or involuntary medication, its use requires a legal authority that may not be available 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, the degree of authority required may necessitate an application to the Court of Protection for this degree of authority.

The direction of development of a service is determined by strategies but, in practice, it tends to be shaped by the interests and enthusiasm of those involved locally as much as by local need. As community care continues to evolve, innovation will require both flexibility and contractual clarity on the part of both commissioners and providers.

# Appendix 1: Instruments contributing to assessment

This is a summary 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 for/by some of the people they see. This account is neither definitive nor detailed: for that, readers should consult other reviews, (Charman and Gotham, 2013; Stoesz et al., 2011) and the inclusion of an instrument is not a recommendation for its use.

The instruments may be used to help gather and formulate the multidisciplinary contributions to a diagnostic assessment. **None provide a substitute for the clinical judgement that is central to diagnosis** ([p24](#)).

It is important to distinguish whether an instrument is being used for:

- clinical purposes – where it provides a framework for the clinician in gathering information for their diagnostic decision
- research– for example where the information is processed, often through an algorithm, to arrive at a decision as to caseness
- screening – where a test is used routinely to identify those who might benefit from further assessment.

Instruments have often been developed for specific purposes or populations, with limited evaluation outside these; in other circumstances, their reliability may be unknown. Examples are where they:

- have been developed for a specific 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 clinical diagnostic use
- rely on limited testing, for example based on case vs. 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; as they will omit those symptoms that do not discriminate effectively, they cannot be

expected to provide an overall description of the person's full range of characteristics.

Although some of the instruments listed are unsuitable for adult use, they are included because they may have contributed to an earlier, childhood diagnosis.

## Questionnaires

### **Australian Scale for Asperger Syndrome (ASAS)**

A parent/teacher rating tool designed for primary school children who do not have a significant degree of intellectual disability, which was developed by Tony Attwood and is widely used because of its public availability. It has 24 graded questions and a 10-item behavioural checklist. It does not give scores or a cut-off but does alert parents and teachers to the possibility of autism. (<https://www.aspenj.org/pdf/information/articles/australian-scale-for-asperger-syndrome.pdf>).

### **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 (<https://www.hogrefe.co.uk/shop/social-communication-questionnaire-85199.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 and Gruber, 2012). Developed by John M. Constantino (<https://www.hogrefe.co.uk/shop/social-responsiveness-scale-second-edition-srs-2.html>).

## **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.

The AQ-10 uses ten of the AQ's more discriminatory items and is recommended by NICE (NICE, 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 ([https://www.autismresearchcentre.com/arc\\_tests](https://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). It has an acceptable level of sensitivity and specificity in adult patients attending a mental health service, albeit with a higher threshold than originally proposed (Brugha et al., Accepted for publication).

## **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., 1988). Available from [PRO-ED Inc.](#)

# **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/carers so that there is a focus on the presentation in early childhood as well as the current state. It is a diagnostic instrument that provides a framework to consider a lifelong assessment of autism characteristics. It excludes items not immediately relevant

to this and, over 1–2 hours, allocates each symptom a score that can be used in a well-tested diagnostic algorithm (Lord et al., 1994). Designed originally 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](#) or [Pearson](#).

## **Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2)**

A standardised interview and observational measures, that complement the history taken with the ADI-R. The interview takes 30–60 minutes (with an additional 20 minutes for scoring), and is a combination of activities and conversation designed to elicit, describe and rate the features of ASD using a standardised kit. A set of five modules covers 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 focused on the social and communicative items. The scale's reliability and validity, achieved by specific training, make it one of the main research tools, although it appears to be less sensitive with adults with Asperger syndrome (using Module 4) (Hus and Lord, 2014). Further information about training is available from [Hogrefe](#) or [Pearson](#).

## **Diagnostic Interview for Social and Communication Disorders (DISCO)**

A structured interview that, like the ADI-R, gathers and synthesises information from an informant, but rather than focusing on the diagnosis of autism, it makes a broader assessment of developmental disabilities. Taking 1-2 hours to administer, 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. Developed by Lorna Wing and Judith Gould, a shorter form (taking about an hour) is in preparation ([www.autism.org.uk/disco](http://www.autism.org.uk/disco)).

## **The Handicaps, Behaviour and Skills (HBS) schedule**

An early diagnostic scale produced by Wing and Gould which was superseded by their development of the DISCO, it assessed functional ability as well as autistic symptoms.

## **The 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).

## **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 co-occurring 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). A DSM-5 compatible version for adults is in preparation.

## **The Autism Clinical Interview for Adults (ACIA)**

This is a pair of semi-structured interviews for a subject and an informant (a relative/carer who knows the subject well) to cover 31 ASD items and a further 20 items about co-occurring conditions. Rather than asking a single question about a symptom, it provides a range of probes that a clinician can draw on until they are comfortable that they have a representative answer. Derived from the Family History Interview, a research instrument, the ACIA takes 60-90 minutes to complete and the instrument and training are available from Newcastle University; contact [jeremy.parr@newcastle.ac.uk](mailto:jeremy.parr@newcastle.ac.uk).

## **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) completed by the individual in advance. It incorporates the DSM-IV criteria but also draws on additional symptomatology to give a higher threshold. It was developed by, and is freely available from, the Autism Research Centre (Baron-Cohen et al., 2005) ([www.autismresearch-centre.com/arc\\_tests](http://www.autismresearch-centre.com/arc_tests)).

## **Diagnostic Interview Guide for the Assessment of Able 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 a psychiatrist who is seeing someone whose autism is clear-cut. It is supported by an online training resource (although the latter is restricted to College members). Both can be accessed through the College website: [Interview Guide for the Assessment of Able Adults with ASD](#).

## **The Neuro-developmental Section of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN ND)**

Additional sections on autism and ADHD in adulthood are being added to the SCAN interview (developed by the WHO from the PSE-9 interview). It extends psychopathology

semi-structured interviewing to the collection of data on symptoms of autism in adults, and particularly lends itself to assessing co-occurring disorder. Designed as an interview for adults, there is provision to gather information from an informant if available. WHO-coordinated evaluation studies are under way (Brugha, 2018).

### **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 the manual (Kraijer, 1997).

### **Asperger Syndrome Diagnostic Interview (ASDI)**

This brief interview explores six key domains that Gillberg associated with Asperger syndrome. It is described as a screening rather than a diagnostic instrument (although often cited as the latter) (Gillberg et al., 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 his colleagues, it is self-taught from booklets that, in the UK, may be obtained from [Winslow Press](#) and [Hogrefe](#).



# Instruments to assess associated developmental disabilities

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

## The Autism Research Centre tests

The Autism Research Centre (Cambridge, UK) has developed a series of tests of individual abilities ([www.autismresearchcentre.com/arc\\_tests](http://www.autismresearchcentre.com/arc_tests)) some of which 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** – assesses 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](#).

# Appendix 2: Psychiatric training objectives

## Introductory statement

The aim of this component of the document is to support psychiatrists when developing the skills and knowledge they require to work in the field of autism within their existing practice.

As psychiatrists, they should already have skills in developing formulations, managing complex cases, and liaising with other teams and agencies, notably in mental health and social care to enhance holistic care. They should be able to use the biopsychosocial model and know the range of psychotherapeutic approaches potentially available within the MDT.

They will also have expertise in working with patients, their families, and networks in order to promote their mental wellbeing. This will already include experience of patients with a range of mental and behavioural disorders, who may also have neurodevelopmental disorders which require a developmental perspective (examples of which are autism, ADHD, tic disorders, speech and language disorders, and specific learning disorders).

In developing their expertise in working with autistic people, the psychiatrist requires a knowledge of the theoretical aspects of mental health as it affects autism, including psychological, social, and neurobiological aspects, and its application in both a clinical and an advisory capacity, as well as to the adaptation of therapeutic interventions.

Given that there is specific mention of autism in mental health and other legislation, the psychiatrist needs to have a knowledge of this (for their relevant jurisdiction) as it concerns autism, including the associated codes of practice and statutory guidance.

## Learning outcomes [for all psychiatrists]

1. Acquire the ability to recognise the spectrum of features and behavioural characteristics of autism, irrespective of gender, age or ability, both when occurring as a single diagnosis and when accompanied by other neurodevelopmental or psychiatric conditions.

**Key capabilities** (mapping to GPC of Domain 2 Professional Skills/clinical skills: history taking, diagnosis and medical management – Domain 9: Capabilities in research and scholarship):

- a) A knowledge of the core features of autism and of other neurodevelopmental disorders.

2. Demonstrate the ability to interview and work with autistic people and those around them, using a person-centred approach and making appropriate adjustments.

**Key capabilities** (mapping to GPC of Domain 2 Professional Skills/communication and interpersonal skills and Domain 2 Professional Skills/Dealing with complexity and uncertainty):

- a) Appreciate strengths and limitations of the communication of autistic people and to adapt their own style accordingly (including the use appropriate supports (e.g. as set out on [p30](#) and [p36](#))).
  - b) Appreciate the need for appropriate settings (e.g. as set out on [p30](#)).
3. Acquire a familiarity with the various services available to autistic people (both within and outside the health service including, for example, social services, education, employment and third sector agencies) and demonstrate the ability to work with them to the benefit of the individual.

**Key capabilities** (mapping to GPC of communication and interpersonal skills):

- a) Demonstrate the ability to work with other disciplines and agencies with and for an autistic person.
  - b) Demonstrate the ability to work with a multidisciplinary team around an autistic person, contributing to a comprehensive assessment.
4. Acquire an expertise in appropriately adapting the management (psychological, pharmacological, social and environmental) of mental disorders when they occur in autistic people.

**Key capabilities** (mapping to GPC of Domain 2 Professional Skills/clinical skills/Prescribing medicines safely).

5. Acquire a familiarity with the legislation of the relevant jurisdiction.

**Key capabilities** (mapping to GPC of Domain 3 Professional Knowledge/national legislative requirements):

- a) The knowledge and ability to advise the courts concerning the nature of a person's condition, its relevance to behaviour, and the best ways of treating and/or managing the condition and fostering the person's development.

6. For those in specialist autism services:

- a) The ability to carry out a comprehensive assessment of an autistic person (usually as a member of a multidisciplinary team) including the more subtle and complex presentations. This will include a standardised approach to taking a developmental history and observational assessment.

A more detailed account is provided by three of the UK administrations which set out the levels of skill, knowledge and behaviours expected in different occupational roles (Department of Health and Social Care, 2019; NHS Education for Scotland, 2015; Welsh Government, 2017)

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