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Aims

The main aims of this chapter are: (1) to give an account of the latest attempt to define and characterise the set of behaviours associated with what are now officially referred to as ‘autism spectrum disorders’; (2) to outline some of the reasons why this change in name, and other major changes to the definition and description of ‘autism’, have been made; (3) to indicate the mainly positive but some negative reactions to the changes; and (4) to indicate how DSM-5 diagnostic criteria and descriptors may apply in practice to a very diverse group of people. An underlying aim of the chapter is to emphasise that because we don’t know enough to be able to say definitively what autism is, the concept and definition will undoubtedly change again in future years.

INTRODUCTION

Giving a name to anything, such as a kind of tree, an emotion, a colour, a mental health condition, involves agreeing on what the named thing is. Naming something is driven by the need to communicate about it, although the reasons why we may need or want to communicate about something are extremely varied. In the case of a mental health condition, the pressure to communicate about it is driven first and foremost by the need to identify the distinctive set of behavioural anomalies or difficulties adversely affecting a particular group of people, so as to develop ways in which their difficulties may be prevented, overcome, or alleviated. (For elaboration of these reasons, see Chapter 11, especially the section entitled ‘Why Diagnose?’)

Sometimes we need to name something tentatively before we can say definitively what it is, improving our understanding over possibly long periods of time. Moreover, improved understanding may result in re-naming something, so as to better represent an updated concept of what the named thing is. For example, astronomers used to refer to what’s-out-there-in-space as ‘the ether’, whereas nowadays astrophysicists might refer more specifically to ‘dark matter’ (though they are still not able to say exactly what dark matter actually is). The terms used to refer to what in this book is generally called ‘autism’ are of this kind: from ‘childhood schizophrenia/psychosis’ to ‘early childhood/infantile autism’ to ‘pervasive developmental disorders’ (PDDs) including Asperger syndrome, autistic disorder and PDD-NOS – these are all terms that have in turn been superseded.

This terminological instability results from the fact that autism presents as a complex behavioural condition which we are as yet unable to fully understand or explain, despite the considerable progress that has been made since it was first tentatively identified. Nevertheless, we are getting better at characterising the kinds of behaviour that invariably or commonly occur in the group of people that clinicians and others see as ‘autistic’. This progress is reflected in the latest attempt to characterise what autism is and to establish evidence-based guidelines for the diagnosis of individuals who may be described as autistic.
In the next section, these guidelines are presented first. Justifications for the latest changes made to the diagnostic terminology and criteria for autism will then be outlined. Some positive and some negative reactions to some of these changes will be briefly considered. The chapter ends with short descriptions of three individuals all of whom might qualify for a diagnosis of ‘autism spectrum disorder’ despite being more different from each other than they are alike.

**DSM-5 CONCEPT AND DEFINITION**

**Diagnostic Criteria for Autism Spectrum Disorders**

After extensive consultation and deliberation by mental health experts over a 14-year period, a fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5 – note use of the Arabic numeral) was published by the American Psychiatric Association in 2013. In DSM-5, the concept of ‘autism’ reverted from the subtypes model expounded in DSM-IV (1994) and maintained in DSM-IV-TR (2000) (see Chapter 1) to the earlier concept of a spectrum of autism-related behaviours. DSM-5 diagnostic criteria for autism spectrum disorders (ASD) are shown in Box 2.1.

**Box 2.1 DSM-5 diagnostic criteria and descriptors for autism spectrum disorders**

**Diagnostic Criteria:** All four criteria, A, B, C, and D must be met for a diagnosis of ASD to be made.

*A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all three of the following, currently or by history (NB: examples are illustrative, not exhaustive).*

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation, to reduced sharing of interests, emotions or affect,¹ to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts;

(Continued)

¹Words or phrases in bold type on first occurrence can be found in the Glossary.
to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:

1. Stereotyped or repetitive speech, motor movements, or use of objects (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).

C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities).

D. Symptoms together limit and impair everyday functioning.

Descriptors: Severity Levels and Specifiers

Severity of socio-communicative impairments:

Level 1: ‘Requiring support’: Without supports in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.

Level 2: ‘Requiring substantial support’: Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.

Level 3: ‘Requiring very substantial support’: Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.

Severity of restricted, repetitive behaviors (RRBs):

Level 1: ‘Requiring support’: RRBs cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB’s or to be redirected from fixated interest.

Level 2: ‘Requiring substantial support’: RRBs and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere
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with functioning in a variety of contexts, Distress or frustration is apparent when RRBs are interrupted; difficult to redirect from fixated interest.

Level 3: ‘Requiring very substantial support’: Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly.

Specifiers
• with or without accompanying intellectual impairment
• with or without accompanying language impairment
• associated with known medical or genetic condition or environmental factor
• associated with another neurodevelopmental, mental, or behavioral disorder
• with catatonia
• onset (eg with regression) is to be described

APA (2013) with permission

Changes from DSM-IV and DSM-IV-TR to DSM-5

Seven major changes were made, as outlined below.

1. Whereas both versions of DSM-IV conceptualised autism as a set of related but diagnostically distinct subtypes of ‘pervasive developmental disorders’ (PDDs), DSM-5 abandoned the subtypes concept, returning to the earlier notion – widely current from the late 1980s onwards – of autism as a spectrum of characteristic behaviours.

2. For a diagnosis of ASD, behaviour must be significantly impaired in two, instead of three, major ways. Specifically, what were described separately in DSM-IV as ‘social interaction impairments’ and ‘communication impairments’ are now combined as ‘deficits in social communication and social interaction’ (see A. under ‘Diagnosis criteria’ in Box 2.1).

3. Restricted and repetitive behaviour remains as an essential element in the diagnostic criteria for ASD (see B. under ‘Diagnostic criteria’ in Box 2.1). However, sensory behaviours are now included as one of the most common forms of restricted, repetitive behaviours (RRBs) (see B.4 under ‘Diagnostic criteria’ in Box 2.1). Sensory anomalies were not noted in DSM-IV, although mentioned in earlier definitions (see Chapter 1).

4. Diagnostic criteria for ASD are now supplemented by descriptors. These concern (a) the severity of the criterial impairments or anomalies; and (b) the complexity of an individual’s diagnostic profile in terms of the presence of any additional diagnosable conditions or special circumstances, referred to as specifiers.

5. Delayed or impaired language is listed as a possible specifier instead of being included as a possible manifestation of ‘communication impairment’.

6. It is explicitly recognised that the behaviours essential for a diagnosis of ASD, although present from early childhood and retrospectively identifiable, may not ‘become fully manifest’ and a cause for concern until ‘demands exceed limited capacities’.
A new diagnostic category, termed social (pragmatic) communication disorder, is introduced. This diagnosis is intended to apply to individuals who have the socio-emotional-communicative (SEC) impairments and anomalies typical of ASD, but not the RRBs.

WHY THE CHANGES?

In what follows, justifications for each of the seven major changes outlined above are considered in turn. There follows a short section summarising some reactions, both positive and negative, that followed publication of the DSM-5 concept of, and criteria for, ASD.

Why Abandon Subtypes in Favour of a ‘Spectrum’?

Fuzzy boundaries
The major problem with the subtypes concept was that it proved difficult in practice to make unambiguous distinctions between the three putative subtypes of autism (‘Asperger disorder’, ‘autistic disorder’ and ‘pervasive disorder not otherwise specified’). As a result, the diagnostic labels were inconsistently applied (Happe, 2011). The distinction between ‘autistic disorder’ and ‘Asperger disorder’ (‘Asperger syndrome’ (AS) as it became more commonly known) was particularly problematic in practice. According to DSM-IV, the presence or absence of impaired language ability is critical to the distinction (see Chapter 1). However, there is currently no evidence of a clear cut-off point between autistic disorder and AS in terms of language ability. Rather, there is a continuum of language abilities from superior in some individuals through to good average, to low average, to mild impairment in others, down to moderately, severely, and finally profoundly impaired in yet other individuals. Intelligence, or what will more usually be referred to in this book as ‘learning ability’ – which was also seen as critical to the distinction between autistic disorder and Asperger disorder – also lies on a continuum varying from superior to profoundly impaired.

The lack of clear boundaries between autistic disorder and AS meant that in practice the diagnostic labels were loosely used, with a bias towards inappropriate use of the Asperger label. This bias is understandable, because a diagnosis of AS had more positive connotations than a diagnosis of autistic disorder. The hopes and expectations of parents, teachers and others of a child diagnosed with AS were justifiably quite high in terms of likely ability to do well at school, attend university, find employment and live independently. And expectations are important because to some extent they are self-fulfilling. Understandable as it is, stretching the Asperger label to include individuals fully meeting criteria for ‘autistic disorder’ reduced its meaningfulness and usefulness.

The label ‘Asperger syndrome’ was also over-used at what might be termed the ‘top end’ of the spectrum, where there is no clear boundary between autism and normality/typicality. Moreover, the term gained a certain cachet from the
representation in some popular films and books of people with AS as odd, quirky characters with amazing talents. The upside of the AS label was further enhanced in popular understanding by suggestions that very high-achieving individuals, such as Einstein or Darwin, may have been cases of AS (see Chapter 1). Thus the ‘Asperger’ label risked becoming what Skuse (2011) referred to as ‘autism for the middle classes’.

Over-emphasis on the competencies of people warranting a DSM-IV diagnosis of AS, combined with under-emphasis of the downsides of being constitutionally obsessive and poor at social relationships (such as vulnerability to bullying at school and to loneliness, sexual frustration, and anxiety and depression in adulthood) undoubtedly contributed to over-use of the label in everyday speech. An example of the damage that may be caused by incautious use of the label ‘AS’ is outlined in the thumbnail sketch of ‘Shaun’ below.

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**Box 2.2 ‘Shaun’: Not autistic – just unhappy**

Shaun was 4;0 when his parents broke up after a tempestuous relationship. Shaun stayed with his mother, and his father was forbidden access to Shaun and his younger sister while being assessed for a mental health disorder. Shaun was considered too young to be told why he could not see his father, but he kept a photograph beside his bed and often asked why he couldn’t see his daddy.

When Shaun started at primary school shortly afterwards, his mother mentioned that she and Shaun’s father were separated, but did not give any details. She knew that Shaun was somewhat withdrawn, spending hours playing computer games or drawing imaginary monsters. And he had not yet brought home any friends to play with after school. But he had a close loving relationship with her and also with his younger sister.

When attending the first parent–teacher evening, therefore, Shaun’s mother was shocked and upset when the teacher suggested that he might have ‘Asperger syndrome’ and should be seen by an Educational Psychologist. Fortunately, the psychologist’s opinion was immediately reassuring. However, she suggested to Shaun’s mother that she should be more open with Shaun’s teacher concerning recent family problems, and enlist her help to draw Shaun out of his shell at school. This advice bore fruit. As things settled down at home, and Shaun got to see his father on a regular basis, he became more outgoing at school, had a circle of friends – and was happy!

Was the teacher wrong, therefore, to voice her suspicion that Shaun might have ‘Asperger syndrome’? Probably yes, in view of the fact that Shaun was so new into school and she knew very little about his family background. She might have done better to have encouraged the mother to talk about why – in her view – Shaun was withdrawn at school, and to suggest a need to ‘keep an eye on him’, preparing cautiously for the possibility of a psychological assessment at some later date. It is all too easy to stick labels onto people – and much harder to remove them later. On the other hand, early recognition that certain problems may exist, and early but cautious intervention, can be critical for long-term outcomes (see Chapter 12).
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Diagnostic instability
An additional though very different problem in applying the subtype labels was that individuals change – sometimes showing remarkable improvement, sometimes regressing (Seltzer, Krauss et al., 2003). One individual – I’ll call him Matt – known to me over many years, not only shifted from an authoritative DSM-IV diagnosis of ‘autistic disorder’ in early childhood to a diagnosis of ‘Asperger syndrome’ in later childhood, but now – as a young adult – no longer qualifies for any ASD-related diagnosis at all (see Box 2.3). How did this come about? I have to say that everything was in Matt’s favour: a very early diagnosis; parents able to afford every possible kind of appropriate help; a supportive extended family; and parents themselves, both teachers, who became more expert than the experts in understanding autistic behaviour and who devoted themselves to helping Matt (cf. Orinstein, Helt et al., 2014). Other cases of optimal outcome (OO), although rare, are now well documented (Fein, Barton et al., 2013). As in Matt’s case, residual traces of ASD remain, but are so attenuated as not to warrant an ASD diagnosis (Tyson, Kelley et al., 2014).

Box 2.3 ‘Matt’: From early autism to an ‘optimal outcome’

I knew Matt’s parents as friends, and was delighted for them when their son Matthew was born. I didn’t see much of the family in Matt’s first couple of years – we were living in different places and pre-occupied with juggling children and work commitments. However, when Matt’s parents moved to teaching jobs in the university town where I was working, we caught up with each other. Almost immediately, Jenny told me that she was worried about Matt because although active and clearly intelligent (he could make aeroplanes and monsters out of Lego precociously early), he wasn’t talking. ‘If he wants something,’ Jenny told me, ‘he takes my hand and moves it towards whatever he wants. He lives in a bubble – almost as if other people don’t exist. He’s been diagnosed with “autism/severe language disorder,” and he’s on the waiting list for a place in a play therapy group. But Don and I want to be helping him now – at home. Can you suggest things we might do?’ I subsequently visited the family regularly for a while, spending time with Matt and gradually engaging him in the kind of play which can be helpful for very young children with possible autism (described in Box 12.3). Matt’s parents quickly took over from me, coaxing Matt out of his shell. They also paid for speech therapy sessions, and sometime after his third birthday, Matt started speaking – in sentences! However, he remained socially aloof, being more interested in things than in people, and on entering school was re-diagnosed with ‘Asperger syndrome’. Now in his mid-20s, although still ‘a little bit obsessive’ according to his parents, Matt no longer warrants a diagnosis of any form of autism. He has a degree in Computer Science, a well-paid job and plays in a band. No girl friend – as yet (but maybe next year...).

Advantages of the spectrum concept
The concept of autism as a spectrum made up of individuals having in common certain kinds of unusual or impaired behaviours, while varying widely in many critical ways, had been argued for as long ago as 1979, as described in Box 2.4.
Box 2.4 The Camberwell study

In 1979, Wing and Gould published a report of a large-scale study of children with special educational needs (aka 'exceptional children') attending schools in the London area of Camberwell. In this study, the clinician-researchers identified some children who had all the behavioural impairments originally described by Kanner (1943), including impaired language and low learning ability; other children who were more able in terms of language and learning abilities, but who were nevertheless 'autistic' in that they had what Wing and Gould termed the defining 'triad of impairments affecting social, communicative and imaginative behaviour'; and some children who had some but not all of the behavioural impairments characteristic of autism. Wing and Gould did not see these roughly differentiable groups as clear-cut subtypes of autism. Instead, they wrote first of a continuum of autism-related problems, later preferring the term 'the autism spectrum' to refer to the varied forms that autism might take.

In their report of the Camberwell study, Wing and Gould (1979) stressed the importance of explicitly recognising that there is a continuum of severity with which autism-related behaviours occur; also that language ability and learning ability vary, covering the full range from superior to profoundly impaired. Finally, Wing and Gould noted that some but not all of the children had additional physical disabilities, medical problems or developmental difficulties and that these, too, might be more or less severe.

In sum, Wing and Gould’s report prefigured not only the DSM-5 concept of a spectrum of autistic disorders, but also the descriptors needed to provide a full account of each individual’s problems and needs.

The term ‘spectrum’ allows for the fact that people whose behaviours conform to Asperger’s descriptions are clearly very different from people conforming to Kanner’s descriptions – as different from each other as the colours at opposite ends of the spectrum of visible light. At the same time, just as violet morphs into blue, then into green, yellow, orange and finally red, the word ‘spectrum’ captures the fact that there are no clear boundaries between the different forms that autism takes.

The term ‘autism spectrum’ was, in fact, increasingly commonly used from the 1990s onwards. Some clinicians and researchers preferred to use the term ‘autism spectrum disorders’ (plural), allowing for the possibility of the identification of discrete subtypes at some future time. Others used the term in its singular form, anticipating DSM-5 usage.

Why Only Two Core Impairments?

Social interaction and communication are inextricably related; all successful communication involves social interaction, whether directly or indirectly; and all truly social interaction involves communication of some kind or another. Certainly, communication can be unsuccessful and fail to achieve the intended interaction. For example, sending messages about humankind into space has not yet, so far as
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one can tell, achieved the aim of making social contact with aliens. Equally, not all interactions between people are social and therefore communicative. For example, two people might accidentally collide on a crowded street, thus physically interacting but not communicating. However, the overlap and mutual dependencies between social interaction and communication are far more compelling than the differences. That is why ‘social interaction impairment’ and ‘communication impairment’ needed to be merged.

Why are Sensory Anomalies Included?

‘Abnormal response to perceptual stimuli’ was listed as one of ‘Creak’s Nine Points’ (see Box 1.1). Similarly, Ritvo and Freeman’s (1977) definition of autism for the National Society for Autistic Children in the USA included ‘Abnormal responses to sensations: any one or a combination of sight, hearing, touch, pain, balance, smell, taste’. Again, the first official criteria for the diagnosis of autism published as DSM-III in 1980 included ‘Bizarre responses to aspects of the environment’. Moreover, first-hand accounts of what it is like to be autistic invariably emphasise peculiarities of sensory-perceptual experience (see Box 3.4, in the next chapter). It is hard to understand, therefore, why sensory abnormalities were not mentioned in DSM-IV, and their re-inclusion in DSM-5 is logical and welcome.

Why Add ‘Descriptors’?

Descriptors indicating the severity and complexity of any one individual’s condition were introduced across most of the mental health disorders listed in DSM-5. In the case of ASD, the combination of diagnostic criteria plus these two sets of descriptors was designed to be sufficiently broad to encompass the whole range of people with autism-related behaviours in all their diversity – to counteract any illusion of homogeneity such as might be fostered by bringing together all forms of autism under the single heading of ‘Autism Spectrum Disorder’. The introduction of descriptors was also specifically intended to add detail to diagnostic profiles informing the development of individualised treatment plans.

Why the Changed Status of Impaired Language?

Until the publication of DSM-5, delayed or impaired language had always been mentioned either as a necessary component of a communication impairment (as in Kanner’s early formulation) or as a possible component of the communication impairment (once Asperger’s descriptions became well known). However, if impaired language is not invariably present in people with ASD, then it makes sense to list it as a specifier rather than under the umbrella of ‘socio-communicative impairment’.

In making this change, the DSM-5 experts were again going along with a change that was already widely accepted in practice. In particular, it had become commonplace
to describe individuals with the hallmark behaviours of autism, but with good
language and intellectual abilities, as having ‘pure’ autism. By implication, those
with additional language (and learning) problems were seen as having ‘autism +
additional problems’.

It may not be immediately obvious why ‘communication’ and ‘language’ are
considered separable, or, to use the more technical term, ‘dissociable’. After all,
human beings communicate via language, pre-eminently, using words and sen-
tences. However, communication is something that we do, using spoken and
written words, for sure, but also by gestures, facial expressions, body movements,
flag-waving, smoke signals, pictorial signs… Language, on the other hand, is some-
thing that we have: a store of words (or signs) and their meanings; our knowledge
of grammar. Asperger (1944/1991) captured this distinction perfectly when he
noted that the individuals he was seeing in his clinic had ‘good grammar and
vocabulary but inappropriate use of speech’. More is said about this important
distinction in Chapter 4.

**Why Allow for Late Diagnosis?**

It has become increasingly common over recent decades for a diagnosis of ASD
to be made quite late in childhood, or in adulthood. DSM-5 diagnostic criteria
specifically allow for this (see C. under ‘Diagnostic criteria’ in Box 2.1), once
again accepting, rather than initiating, a trend that was already well established
in practice. Notice, however, that a diagnosis of ASD still requires that signs of
autism have been present from quite early in childhood, even if identified only in
retrospect.

The increase in late diagnosis undoubtedly largely reflects greater recognition
of mild forms of ASD occurring in able individuals who compensate well, and
who ‘get by’ socially – at least until some life event brings their autism-related
problems under the spotlight. A case where late diagnosis saved a marriage is
outlined in the thumbnail sketch of ‘George’ described in Box 2.5. Another case
of late diagnosis, and the relief it brought to the individual involved, is described
in Chapter 11.

**Box 2.5  ‘George’: Diagnosed with ASD aged 60+**

When Amy was widowed in her late 50s, she sensibly decided that it was no
good sitting around moping. So, among other things, she joined a choir as a way
of getting herself out of the house and meeting new people. She was quite open
about wanting to find a new partner with whom to share her life, and when she
met George, a member of the choir, she thought that they ‘clicked’. He, like her,
was on his own; they both enjoyed making and listening to music... Unlike Amy,
however, George was happy to be on his own. He was recently retired, having

*(Continued)*
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worked as an accountant for the last 40 years. He had two adult children from an early long-dead marriage, and saw them from time to time. A keen naturalist, he enjoyed solitary walks in the countryside. He loved baroque music (Amy was more into ‘the romantics’), and had a large collection of classic performances on vinyl discs which he listened to most evenings. To cut a long story short, Amy moved in with George, and shortly afterwards the pair got married. However, they were soon at odds, mainly because George stubbornly maintained his accustomed way of life, resisting Amy’s suggestions that they go out more, see friends more often. At Amy’s instigation, they attended marriage guidance sessions, where an insightful counsellor suggested that maybe George was ‘slightly autistic’. An equally insightful psychiatrist subsequently confirmed this diagnosis, realising that Amy needed the label to make sense of George’s behaviour, to be able to say to friends ‘Well, he is a bit autistic’. Amy and George now live apart, but in the same town. They are in close touch: enjoying each other’s company on weekly ‘dates’, taking holidays together, and helping out if one or the other of them is unwell.

‘SOCIAL (PRAGMATIC) COMMUNICATION DISORDER’

What is it, and Why is it Mentioned?

According to DSM-5, social communication disorder (SCD) is characterised by ‘persistent difficulties in the social use of verbal and nonverbal communication sufficiently severe as to interfere with social relationships, academic achievement and occupational performance’ (American Psychiatric Association [hereafter APA], 2013). For a diagnosis of SCD to be made, these communication difficulties must have been present from a very early age, though often not noticed until a child enters school. Finally, SCD should only be diagnosed if an individual’s communication impairment is not explicable in terms of learning disability, deafness, autism, or a specific speech or language impairment. Differential diagnosis has, however, proved difficult in practice (Bishop, 2014; Brukner-Wertman, Laor & Golan, 2016). Although SCD was not defined in previous editions of the DSM, problems of communication in the absence of language impairment had long been recognised by speech/language pathologists and therapists (Rapin & Allen, 1983; Botting & Conti-Ramsden, 2003). In this early literature, such children were described as having ‘conversational difficulties’ or, to use the more technical term, problems of pragmatics (see Box 4.2). The term ‘pragmatic language impairment (PLI)’ has, in fact, been in common usage by speech/language pathologists since the beginning of the century. Moreover, the overlap between the newly introduced term ‘SCD’ and the well-established term ‘PLI’ is increasingly recognised by combining them as ‘socio-pragmatic communication disorder’ (SPCD) (Norbury, 2014). For discussion of how SPCD relates to other problems of language and communication, including autism, see Swineford, Thurm et al. (2014).
REATIONS TO THE CHANGES

People with an Existing Subtype Diagnosis and their Families

**Autistic disorder**
People who already had a diagnosis of ‘autistic disorder’, also their families and carers, were unaffected by the change of terminology.

**Asperger syndrome**
Some people with an existing ‘Asperger syndrome’ subtype diagnosis welcomed the changed terminology. For example, Michelle Dawson, a well-known autism researcher, rejoices in being called ‘an autistic’, arguing that it is her *autism* that makes her the person that she is. Similarly, an AS blogger wrote:

> I personally think [the changed terminology] is a good thing... The difference between Aspergers and High Functioning Autism doesn't exist. (www.alexlowery.co.uk/)

Some other people with an existing diagnosis of ‘Asperger syndrome’, however, expressed distaste and dismay at the loss of what for them was the linch-pin of their sense of identity. One such person blogged: ‘The psychiatric bible tells me I am autistic but in my heart I will always have Aspergers.’ And later:

> Aspergers sufferers have been put under a new umbrella called “autism spectrum disorder”, which lumps us in with autistic people who, in some cases, lack the power of speech... (Vaillancourt, 2015)

Some other high-functioning adults with an existing AS diagnosis used social media to form a community of ‘Aspies’, organising their own communication networks and get-togethers, paying expert ‘insider’ attention to each other’s social, communication and sensory vulnerabilities. ‘Aspies’ also constituted a powerful lobbying group, arguing persuasively that they are ‘different’ but not ‘disordered’. The community of high-functioning people with some autistic-like behaviours is not likely to disintegrate with the loss of the AS diagnostic label. So one hopes that individuals such as Matthieu Vaillancourt will in time identify with this group, and cease to mourn.

**PDD-NOS**
For people formerly consigned to the rag-bag subtype ‘PDD-NOS’, the more informative diagnostic terms ‘autism spectrum disorders’ (with its ‘severity’ and ‘complexity’ descriptors) and ‘socio-pragmatic communication disorder’ were generally welcomed.

An interesting discussion of autism-related terms preferred by people with ASD themselves, and their families, can be found in Kenny, Hattersley et al. (2016).
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Professionals

Clinicians
The change from a subtypes model to a spectrum model was largely welcomed by those charged with diagnosing autism. There have been some suggestions that DSM-5 criteria are slightly less sensitive than DSM-IV or DSM-IV-TR criteria, possibly under-diagnosing milder forms of ASD (Mayes, Calhoun et al., 2014; Peters & Matson, 2020), especially in infants and toddlers (de Bildt, Sytisma et al., 2015; Sung, Goh et al., 2018). However, evidence of under-diagnosing is controversial (Mazurek, Lu et al., 2017). In Chapter 11, improvements to assessment tools to increase their sensitivity to DSM-5 criteria, especially in young children, will be described.

Researchers
Some researchers, for example Tsai and Ghaziuddin (2014), argued vehemently in support of the subtypes model of ASD as enshrined in DSM-IV, citing numerous studies in which differences have been found between groups diagnosed with AS as opposed to autistic disorder. Moreover, if subtypes of ASD are no longer diagnosed, it will be increasingly difficult to resolve disputes concerning the existence and validity of these putative subtypes.

APPLYING THE CRITERIA IN PRACTICE

Generalised versus Manifest Behaviour

Descriptions of the criterial features of behaviour presented in diagnostic manuals are highly generalised. So, under A.1. in DSM-5, it is stated that for a diagnosis of ASD to be appropriate there must be ‘Deficits in social-emotional reciprocity, ranging from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interest, emotions, or affect; to failure to initiate or respond to social interactions’. But these phrases do not identify any actual, concrete instances of what might constitute, for example, ‘abnormal social approach’ or ‘reduced sharing of emotions’. This is inevitable because diagnostic criteria are designed to apply equally to children and adults; to those with high intelligence and good language as well as to those with profound language and learning impairments; and to individuals with their own personalities and past experiences in all the different environments in which they might be observed – at home, at school, at work, on holiday, when well, when ill, etc. However, the need to generalise entails that the phrases used in the diagnostic manuals fail to convey the diversity of actual, manifest behaviour that might contribute to a diagnosis of ASD. Below are ‘thumbnail sketches’ of three individuals, whose manifest behaviour differs greatly, while qualifying all three of them for an ASD diagnosis.7

7Numerous other brief descriptions of individuals who are on the spectrum are included in boxes throughout the book.
Mandy, aged eight years, sits passively on her preferred swing in the playground of her special school. When another child approaches, she doesn’t look at the child, but gets off the swing and moves to a corner of the playground with her back to the other children. She rocks stiffly from foot to foot. At one point she utters an odd squeal and flaps her hands excitedly, for no apparent reason. Then she begins to hit her own head with her hand. The adult on playground duty approaches, takes Mandy’s hand to stop her hitting herself, and says: ‘Did you want a swing, Mandy? Look, there’s a swing free now.’ Mandy removes her hand from the adult’s and turns away saying ‘free now’. But she doesn’t go towards the vacant swing. Instead, she runs off, with a clumsy gait, bumping into a smaller child who falls over and begins to cry. Mandy stops running, puts her hands over her ears and stands looking at the weeping child, with an uncomprehending, distressed expression on her face.

Damien, aged 16, is sitting at the dining room table tracing a map of New Zealand with extreme care. He tells his new keyworker that he is taking four ‘A-level’ subjects and expects to get top grades and go to university to study geology. The visitor replies that her own son is, by chance, already studying geology at university, but Damien doesn’t follow this up. Instead, he asks: ‘Did you know that New Zealand is 268,000 square kilometres in size, and two thirds the size of California?’ Damien’s mother comes in carrying a tray with cutlery, glasses, etc. to lay the table, and asks Damien to move his things and feed the dog before tea. Damien complies slowly, putting away his pencils, ruler, tracing pad, etc. carefully in different compartments of a drawer, while his mother waits to put the tray down. He then tips some food into the dog’s bowl, but does not call the dog in from the garden. When it is time for the keyworker to leave, Damien’s mother says: ‘See the lady to the door, Damien.’ Damien rises reluctantly to his feet and walks behind the visitor as far as the front door, immediately turning back without returning her wave.

Archie is in his mid-40s, a bit overweight and with a slightly unco-ordinated gait, but otherwise a very ordinary-looking chap. He is shopping in the local supermarket with his elderly arthritic mother, with whom he lives in a mutually supportive relationship: she owns the house they share, pays the bills, and organises Archie’s life as well as her own, Archie helps with housework, heats up their ‘ready meals’, and assists with shopping. Archie’s mother is pushing the trolley, pausing to lean on it from time to time to consult a shopping list, while Archie waits for instructions about what to fetch. He knows where everything is – or was; but the supermarket has had a makeover and things have been moved around. The changes are very upsetting to Archie, who can’t read the notices above the aisles, and is confused and frustrated when things are not in their usual places. When he can’t find his favourite biscuits, he stands blocking the aisle where they used to be, wringing his hands compulsively and making a distressed whining noise. An assistant asks if he needs any help, but Archie is too worked up to reply, and pushes past her to get back to his mother. The shopping does get done in the end. And for the next several weeks Archie and his mother go up and down the aisles together. It takes Archie several weeks to learn the new layout and resume their old method of shopping – until the run-up to Christmas, when things will, alas, change again.

As stated above, definitions of ASD are necessarily framed in terms of highly generalised descriptions of the key facets of autistic behaviour. There have been various attempts to expand these descriptions to encompass something of the range of manifest behaviours falling under these descriptions. For example, Wing (1996) identified four different subtypes of behaviour covered by the term ‘socio-communicative abnormalities’, as summarised in Box 2.6.
Box 2.6 Wing’s four types of autism-related social behaviour

The aloof group behave as though other people did not exist. They might, for example, obliviously bump into someone who is coming through a door towards them carrying a tray of drinks. They do not respond to, or willingly accept, social approaches from others. For example, an ‘aloof’ 4:0 year-old will struggle to get free if picked up to sit on an adult’s knee. An ‘aloof’ adult may get up and move away if another person sits on a seat beside them.

The passive group are not completely cut off from others. They accept social approaches but do not initiate social interaction. For example, if picked up to sit on an adult’s knee, a 4:0 year-old ‘passive’ child will not wriggle off the adult’s lap, but will prefer to sit facing forwards, avoiding eye contact or face-to-face interaction. A ‘passive’ adult will tolerate having someone come to sit beside them, but will not initiate conversation.

The active but odd group make social approaches to other people, but do so in a peculiar one-sided fashion. Repetitive questioning is a feature of this group, who have the motivation to make social contact but do not have varied means of achieving this. So, for example, an ‘active but odd’ teenager or adult may approach a visitor to their school or college repeatedly asking ‘What’s your name?’ ‘What’s your name?’… A more able individual may monologue about their own special interest, regardless of the other person’s attempts either to join in or to change the subject.

The overly formal, stilted group are highly able adolescents or adults who are excessively polite and formal. They try very hard to behave well and cope by sticking rigidly to the rules of social interaction.

Wing did not see her ‘aloof’, ‘passive’, ‘active-but-odd’ and ‘stilted’ descriptions as identifying discrete subgroups, but rather as typifying points along a continuum of socio-communicative abnormalities/oddities. Moreover, she stressed that – given appropriate intervention and support – individuals’ behaviour often changes over time. For example, the ‘aloof’ child who buries her head in her arms to escape other people (e.g. Mandy, described above) may become a ‘passive’ child who tolerates being touched, and who will hold the teacher’s hand, although never initiating contact herself. And the ‘active-but-odd’ adolescent who initiates conversation, even if clumsily (e.g. Damien), may in time learn the ‘rules’ of acceptable socio-communicative behaviour and achieve less self-centred, albeit somewhat ‘stilted’, interaction.

Similarly, restricted and repetitive behaviours may be described as lying along a continuum from stereotypic movements, commonly referred to as stimming (e.g. rocking, hand-flapping, biting the backs of the hands); to pre-occupation with the manipulation of objects or materials (e.g. turning on light switches or taps, letting sand slide through the fingers, twiddling a drinking straw held very close to the eyes); to insistence on routines (e.g. for eating, dressing, the route taken to school) and maintenance of sameness (e.g. of the arrangement of furniture in a room); to repetitive utterances – idiosyncratic or ostensibly meaningful but inappropriately used;
to restricted interests and strongly preferred topics of conversation (e.g. dinosaurs, railway timetables, military equipment); to behaviour which is adaptive (i.e. constructively useful), such as amassing factual knowledge relevant to an area of legitimate study, or ‘one-track-mindedness’ in pursuing a particular hobby or activity.

SUMMARY

The DSM-5 concept and diagnostic criteria for autism changed from those in DSM-IV-TR in quite radical ways, including the following. First, the concept of subtypes of pervasive developmental disorder was abandoned in favour of the concept of autism as an indivisible spectrum of related conditions. Secondly, a diagnosis of autism spectrum disorder requires that two, rather than three, major behavioural anomalies are present, namely SECs and RRBs. Thirdly, behaviours coming under the heading of RRBs include hyper- and hypo- (i.e. too much and too little) sensitivity to sensory stimuli. Fourthly, individuals satisfying the two basic criteria for ASD are differentiated by two groups of ‘Determiners’: the severity of SEC impairments and RRBs, and the absence or presence of additional specifiers. The most commonly occurring specifiers are recognised as being learning disability and language impairment. Other specifiers include various comorbid medical conditions. Finally, a condition to be known as ‘social communication disorder’ is for the first time recognised in DSM-5 and differentiated from ASD.

These changes, which were agreed upon by experienced clinicians in the field who consulted widely with other ‘stakeholders’ over an extended period, have had a mixed reception. Inevitably, it is those with the negative reactions who have been the most vocal in the first years following publication of DSM-5. In particular, some individuals with an existing diagnosis of Asperger syndrome, or who have committed much of their lives to working with and for people with AS, feel a sense of betrayal. There is also some evidence that DSM-5 criteria may be too restrictive, with the danger that some individuals who should be diagnosed with ASD are not identified using currently available assessment methods. To illustrate the difficulties of formulating diagnostic guidance that is sufficiently general to identify individuals from the bottom to the top of the spectrum, the chapter includes thumbnail sketches of three extremely different individuals all of whom have behaviours warranting a diagnosis of ‘ASD’.