# Autism Spectrum Disorders: Psychological Theory and Research

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To:
Ciss
Pidgeon
Michael


*Ba mhaith liom breith ar eireaball spideóige.*

# Contents

# Preface

A reasonable reaction on picking up this volume might be 'not *another* book on autism!', to which my response would be, as you might expect, that this book is different. Although many books have been written about autism spectrum disorders (ASD), most consist either of descriptions of these conditions with a view to developing understanding and dispelling myths; others present more or less detailed accounts of their authors' own ideas with only passing reference to those of other scientists. Those that do present overviews of different positions tend to be edited volumes where experts in the field present up-to-date reviews of the state of play in their own corner of the field, with little attempt at painting a broader picture. What seems to be missing is a work that provides an overview from a single perspective of the main currents of thought. My first aim in writing this volume is to provide such an overview. I present a summary of the main psychological ideas that have been brought to bear on ASD in recent years and where possible, try to identify actual or potential common themes. The reviews of research are not meant to be exhaustive, but I hope that the selections I have made give a fair reflection of the state of current thinking in each domain. My second aim is to highlight the strengths and limitations of the different approaches and to develop a critical stance in readers that will help them evaluate new material as it appears. Finally, I aim to set out some of my own thoughts about how we should take our ideas forward. Insofar as such a thing is possible, I have tried to present the different theoretical systems in a dispassionate manner and to view my own ideas and those of others in the same critical light. But as the former *Observer* television critic, Clive James, once put it, the ego tends to adjust the light to suit its purposes. My ego is no exception.

No piece of academic work is ever the sole work of its author. Ideas always develop in the context of discussion, debate and collaboration. The thoughts expressed in this book, although my own, have been heavily influenced by encounters with a large number of colleagues and friends, to whom I must express my gratitude. First, I must give equal thanks to Chris Kiernan for giving me my first job as a researcher and for taming my rather adolescent approach to critical evaluation, and to Lorna Wing, who introduced me to the fascinating world of ASD and Asperger's syndrome. Lorna was among the first to advocate a spectrum (and more latterly, a dimensional) view of what was then referred to simply as 'autism'. Her tenacious defence against considerable opposition of this once highly unpopular but now widely accepted idea is an inspiration. Throughout my career as a scientist, I have worked alongside

many other remarkable colleagues, including Sarah Lister Brook, Gillian Baird, Jill Boucher and John Gardiner. My ideas also owe a great deal to the discipline offered by gifted research assistants and students among whom I can count Jackie Briskman, Sarah Grice, Sebastian Gaigg, Jonathan Martin, George Berguno, Dianne Gumley, Paul Holland, Catherine Molesworth, Sophie Lind, Niki Daniel and Esther Strom. On the wider ASD front, I would also like to thank Tony Charman, Uta Frith, Francesca Happé, Pam Heaton, Peter Hobson, Chris Jarrold, Sue Leekam, Peter Mitchell, Derek Moore, Kate Plaisted, Michelle O'Riordan and John Swettenham. And from outside the field of ASD, Barbara Reid, John Versey, Donald Peterson, Marie Poirier, Alan Porter, Zofia Kaminska, James Hampton, Evelyne Thommen and Charles Legg. A special thanks goes to the Wellcome Trust, the Medical Research Council of the United Kingdom and the Department of Psychology at City University, without whose generous support many of my ideas would never have been subjected to the rigours of empirical test. I should also particularly like to thank the Department of Educational and Counselling Psychology, McGill University and the Clinique spécialisée des troubles envahissants du développement, Hôpital Rivière-des-Prairies, Montréal for generously accommodating me during a period of sabbatical leave during which the bulk of the book was written, and of course, my hosts Jacob Burack and Laurent Mottron, who provided insightful comments and encouragement during this process. And finally, thanks to Robert, for his endless patience, love and understanding.

## ACKNOWLEDGEMENTS

# 1 Identifying Autism: From Discrete Entity to Multidimensional Spectrum

In one respect there is no need to write this chapter at all. As this is a book about psychological research and theoretical approaches *to* autism spectrum disorders (ASD), it is tempting to adopt the stance of the mathematician and to say something analogous to 'there exists the set of positive integers 1, 2, 3, 4,..., $n$,..., $n + 1$..., which have the following properties...'; in other words, to assume that such disorders exist and to leave debates about the whys and wherefores of their existence for others, choosing to concentrate instead on their properties. But matters are not that simple. A complex behavioural syndrome is not quite so easily described as the set of positive integers, and definition and explanation are perhaps more closely intertwined in the field of psychopathology than they are in mathematics. Moreover, a grasp of what we mean when we use terms like 'autism', 'autism spectrum', 'pervasive developmental disorder' or whatever is crucial to the development of a critical understanding of the psychological research into these conditions. We need not only to be clear about what is currently understood by these terms, but also to have some idea of how this understanding has evolved over time as well as how such evolution impacts upon and nuances our current conceptualisation of the conditions. What is proposed in this chapter is a discussion of the historical development of the concept of autism followed by an overview of the diagnostic systems currently in use together with a discussion of some of the issues that remain controversial. This will include some consideration of characteristics of the condition that fall outside the strict parameters of the diagnostic systems but which are nonetheless important to understanding them. Finally, there will be some material on early detection of autism and its implications for other areas of research.

## EARLY CONCEPTIONS: THE 'AUTISTIC CHILD'

In the 1940s, in the middle of World War II, two clinical descriptions of psychopathological conditions appeared in the literature, one written in

English and the other in German. The first was by Leo Kanner (Kanner, 1943) in which he described a series of 11 children whom he had seen in his clinical practice, and who were characterised by what he called 'autistic disturbances of affective contact'. This description laid the foundation for all the work that forms the basis of the remainder of this book and brought to general awareness the notion of 'the autistic child'. Kanner was not the first to describe children like these. Wing (see e.g. Wing, 1993) has long argued that Victor, the 'Wild Boy of Aveyron' first described by Itard (Lane, 1977), may have had the condition described by Kanner, and U. Frith (2003) provides an insightful survey of a number of historical figures, including Victor (and a fictional one – Tommy from the 1970s rock musical by The Who), who in all probability had autism. Hobson (1990b) cites a description by Melanie Klein of a young boy called Dick. She describes him as being devoid of affect, undisturbed at being separated from his nurse, showing no desire to be comforted. He did not play and '. . . several times ran round me, just as if I were a piece of furniture . . .' (Klein, 1930/1975, cited in Hobson, 1990b). Klein's description resembles that given by Kanner, but although Klein provided some important observations about Dick's condition (most notably that she thought it was constitutional in origin, and that it involved disruption of interpersonal processes), her account was of a single case, and so did not carry with it the notion of a syndrome – a cluster of symptoms that can be identified in different cases – and so did not enter the scientific literature in the same way that Kanner's observations did. It was Kanner's terminology and the condition he described that gradually became widely known, and both his description and the diagnostic scheme he proposed have formed the basis of our conception of autism ever since. The beauty of Kanner's account is that it captures very concisely the picture of a child with what we now sometimes call 'Kanner-type autism' and who would probably meet currently accepted criteria for autistic disorder.

The children described by Kanner were characterised by a failure to develop the kinds of emotionally charged interpersonal relations that usually become part of a child's behavioural repertoire. They tended to treat other people as objects rather than as human beings like themselves. They also showed characteristic patterns of speech and language use, being either mute or having delayed language development. And they also often displayed what he called immediate and delayed echolalia. Immediate echolalia is the tendency to repeat back what has just been heard or, in the case of a longer sentence, just the last few words. Delayed echolalia is the repeated use of a phrase such as 'go for a walk now' that was heard some time previously and that appears to bear no relation to the current context. A marked, and important, aspect of these children's use of language was the tendency to reverse pronouns. In normal conversation, when I speak about myself, I call myself 'I' or 'me', and refer to my interlocutor as 'you'. The other person, by contrast, does the reverse, referring to me as 'you' and to him/herself as 'I' or 'me'. Such

adjustments of pronoun use according to the role of the speaker are hard for many individuals with autism, who tend to refer to themselves consistently as 'you' and to others as 'I' or 'me'. It is as if they regard words like 'I', 'me' and 'you' as names or labels rather than as role-determined attributions. Kanner also noted what he called an 'obsessive insistence on sameness', where children would attempt to return a changed situation to its original state and often became quite distressed when a well-practised routine was altered in some way, such as when they were taken to school by a different route. A related characteristic was a tendency for the behaviour of his children to be repetitive and lacking in imagination. When given a toy car, for example, children like those he described often prefer to turn it over and repeatedly make the wheels spin rather than to enact a car-related scenario or, rather than pretending that a set of wooden blocks are characters and props in a story, they prefer to line the blocks up or repetitively build and demolish towers.

Two other features observed by Kanner were that the children he described had good rote memory, that is to say that they could recall material without really understanding what it meant, and that they were of normal appearance. This last observation seems an unusual one to make, but the prevailing psychiatric climate of Kanner's time paid a great deal of attention to documenting psychopathological syndromes that were accompanied by characteristic facial features. In that context, it was striking that children who exhibited such markedly atypical behaviour should not be in any way unusual in their physical appearance. The topic of memory will be dealt with in more detail in Chapter 7.

Thus, the picture we get from Kanner's clinical description is of a child who is unremarkable in appearance but who seems indifferent to other people, often interacting with them only to obtain something he cannot get for himself. Spontaneous behaviour is markedly repetitive, with the child preferring to impose his own routines, which lack spontaneity and imagination. Language sometimes fails to develop, but when it does, it has the particular characteristics of immediate and delayed echolalia and pronominal reversal described above, and is often used in a way that has no obvious communicative function.

Most research into autism carried out in the 1950s, 1960s and 1970s recruited samples of children who more or less fitted the clinical picture of the syndrome described by Kanner. This work attempted to refine his descriptions with the aims of gaining greater understanding of underlying difficulties and of providing a richer description in the hope of improving diagnosis and treatment. Particular patterns of cognitive processing were demonstrated in a series of experimental investigations conducted by Hermelin, O'Connor and colleagues (see Hermelin & O'Connor, 1970), who observed difficulties in cross-modal processing and processing of temporally patterned material as well as difficulties in encoding and using meaningful aspects of information. The

methods used to arrive at this conclusion were drawn from mainstream experimental psychology and involved precise experimental manipulation of variables in order to tap processing that was hypothesised to be spared or impaired.

Other approaches to assessing autism-specific aspects of cognitive processing employed standardised tests of intellectual function where profiles of performance across subtests are evaluated. Among the most widely used tests of intellectual functioning are the scales of intelligence known as the Wechsler scales – the Wechsler Pre-School and Primary Scale of Intelligence (WPPSI), Wechsler Intelligence Scale for Children (WISC) and Wechsler Adult Intelligence Scale (WAIS). All these tests consist of sets of subscales, which can be grouped into those that measure verbal skills or non-verbal (or 'performance' in the Wechsler terminology) skills. Level of achievement on these tests is usually expressed not in terms of raw numbers of test items passed, but in normative terms, i.e. how an individual's performance compares with that of an appropriate sample taken from the typical population. Thus, the performance of a child aged 5 years 5 months would be compared to that of a random sample of children of that age recruited from the general population. A characteristic of intelligence tests like these is that typically, for any one individual, normed scores tend to be rather similar across individual subtests. So someone who scores highly on one subtest will tend to score highly on all the others. This is usually not the case for children with autism. Atypical profiles across Wechsler subtests were reported by Bartak, Rutter and Cox (1975) who compared children with a diagnosis of autism but who had non-verbal IQs greater than 70 to dysphasic children who had problems with language. The difference in levels of attainment between verbal and performance tests was greater for the children with autism than the comparison children, and, moreover, the former group were observed to perform significantly less well than the latter on the Comprehension, Similarities and Vocabulary subtests of the WISC and better (but just short of statistically significantly so) on the Block Design subtest. This discrepancy between verbal and performance IQ in the children with autism but not the comparison children was also found for the results of the Peabody Picture Vocabulary Test (a test of receptive vocabulary) and the Coloured Progressive Matrices (a test of non-verbal intelligence, see Raven, 1996). Similar findings to these have been reported since the original study of Bartak et al. (see Manjiviona & Prior, 1999), with minor differences in emphasis depending on the overall level of functioning of the ASD participants being tested. With the advent of a broader conception of autism (see below), intellectual profiles have been used in an attempt to differentiate subgroups in the autism spectrum. But for individuals who fit the picture of autism presented by Kanner, it remains true that relatively enhanced performance can be found on tasks such as Block Design or matrices-type tests, which are visuo-spatial in nature (see Figure 5.2 for an example from the Block Design Test).

## FROM DISCRETE ENTITY TO SPECTRUM OF RELATED CONDITIONS

The widespread consensus that prevailed up until the late 1980s – that the syndrome described by Kanner was a distinct psychopathological entity with a prevalence of about 4 per 10 000 children (Lotter, 1966; 1967) – was first challenged in an epidemiological study of the school-age population of the Metropolitan Borough of Camberwell in south London by Wing and Gould (1979). They found a 'history of typical autism' in 4.9 out of 10 000 children, but with a broader definition of impaired reciprocal social interaction ('social impairment' in Wing & Gould's terminology), the prevalence rate rose to 21.2 per 10 000. Two related developments followed from these observations. The first was that, far from being a discrete entity with clear boundaries, the syndrome described by Kanner represented a particular manifestation of a wider set of conditions that shared certain features even if they did not all express all of them in the same way. The second development was an attempt to characterise the factors unifying the different manifestations of this wider set of conditions. To this end, Wing & Gould proposed that autism was one of a spectrum of conditions, all of which were characterised by a triad of impairments in social, imaginative and symbolic functioning accompanied by repetitive behaviours. The identification of a broader set of parameters within which to conceptualise the syndrome described by Kanner led Wing and her colleagues to search for other conditions, which although not identical to Kanner's, could nonetheless be considered as other manifestations of impairments of elements of the triad. It was this search that raised the profile of what has now become known as Asperger's syndrome or Asperger disorder.

The next observer after Kanner to use the term 'autistic' in the context of child psychopathology was Hans Asperger (Asperger, 1944/1991). His paper was in German and unsurprisingly did not receive much attention in the English-speaking world until Wing's (1981) clinical account of what she termed 'Asperger's syndrome' (although see Bosch, 1970; Van Krevelen, 1971). Asperger described four cases of adolescents whom he described as having 'autistic psychopathy'. Although the cases he described were in many respects quite different from those described by Kanner, most notably in the domain of language and communication as well as in overall level of intellectual functioning, the common thread linking the two was the characteristic disconnectedness from other people to which both authors gave the term 'autism', a term first employed by Bleuler (1911) to describe the retreat into a world of their own that he observed in people with schizophrenia. Both Kanner and Asperger noted that their patients were curiously disconnected from other people; Kanner's children often treating others like objects and Asperger's adolescents being wrapped up in their own interests, with little care whether or not another person shared their fascination. Although Asperger did not list specific criteria for the diagnosis of the condition he described, Wing (1981)

identified eight points in his account. These are listed in Box 1.1 and paint a picture of an individual of normal intelligence with good verbal communication skills but with a long-winded and pedantic style and odd intonation. There was also evidence of circumscribed interests on odd topics, the pursuit of which took up much of the individual's time. Asperger also noted impaired gross motor functioning and a lack of common sense. But the most striking feature of the condition remains the social oddity and lack of empathic reciprocity with others and it is this characteristic that led Wing and colleagues to consider that the conditions described by Kanner and by Asperger to be facets of a common underlying set of factors.

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**Box 1.1.** Characteristics of Asperger's syndrome as listed by Wing (1981)

- More common in boys
- Normal age of onset of speech
- Impaired non-verbal communication
- Flat intonation and absent or large, clumsy gestures
- Impairment of two-way social interaction
- Repetitive activities and resistance to change
- Poor motor coordination
- Clumsy, odd gait and posture
- Circumscribed interests with good rote memory for facts on narrowly defined or unusual topics
- Bullied at school because of perceived eccentricity

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Although Asperger's syndrome and autism of the kind described by Kanner are perhaps the most widely known forms of ASD, there are other conditions that have been described in the literature and which overlap to a greater or lesser extent with the other conditions in the autism spectrum. These include dementia precocissima (De Sanctis, 1906; 1908), dementia infantalis (Heller, 1908), childhood schizophrenia (Bender, 1947) and childhood psychosis (Creak, 1963). More recently, Rourke (1989) identified a syndrome characterised by good rote memory that was used to cope with complex social and non-social situations, unusual prosody in speech and impaired social judgment. As well as attributing this condition to damage to the right hemisphere, Rourke gave it the name non-verbal learning disability (NLD), which is related to developmental learning disability of the right hemisphere (Weintraub & Mesulam, 1983). Wolff and colleagues have described a group of children and adults to whom they have given the label *schizoid personality disorder* (Wolff, 1995; Wolff & Barlow, 1978; Wolff & Chick, 1980). These individuals were characterised by solitariness, lack of empathy, emotional

detachment, mental rigidity and single-minded pursuit of specialised interests, and language difficulties in the area of understanding linguistic devices such as metaphor. In later writings, Wolff acknowledges the overlap between the individuals she described and those described by Asperger. Gillberg and colleagues (Gillberg, 1983) have identified a group of children whose symptomatology overlaps with that of the autism spectrum, whose condition they have labelled *deficits in attention, motor control and perception (DAMP)*. As the term implies, children who are given this label are of normal IQ, have difficulty focusing their attention, are hyperactive and impulsive, experience gross motor difficulties and may show features of other developmental psychopathological conditions including those from the autism spectrum. A further group of individuals from what Bishop (Bishop, 1989; Bishop & Norbury, 2002) has called 'the borderlands of autism' are those described as having semantic–pragmatic disorder or semantic–pragmatic syndrome, and who now tend to be described as having pragmatic language impairment (PLI). The initial published descriptions of such children led Lister Brook and Bowler (1992) to conclude that they were probably a manifestation of the autism spectrum, but more recent studies have shown that although some children whose language is pragmatically impaired meet current criteria for autistic disorder or pervasive developmental disorder, many do not (Bishop & Norbury, 2002). All these conditions overlap to some extent with the autism spectrum, and the extent of their overlap will provide clues not only to a finer delineation of the necessary factors for a diagnosis of autism but also for a better understanding of the mechanisms underlying its development. But both because of the relatively small amount of research into these conditions, and because they are on the periphery of the autism spectrum, they will not be considered in any detail here.

Wing and Gould's characterisation of autism as a spectrum of conditions (later to include Asperger's syndrome) was initially controversial, but has now entered into mainstream thinking where the term *broader phenotype* is currently used to describe individuals who may not meet strict criteria for autistic disorder or Asperger's syndrome but who nevertheless show sufficient features of these conditions to suggest that they share an underlying pathology. Such acceptance of a broader spectrum of autism-related conditions has had repercussions not only on how we think about explaining their underlying characteristics, but also on how common these conditions are in the general population. We have already seen that early studies of what proportion of the population might have autism gave a prevalence rate of about 4 per 10 000 (Lotter, 1966; Wing & Gould, 1979). However, as Rutter (2005) points out, these early studies had a number of shortcomings, principally that they were conducted on relatively small samples, that they used a fairly strict definition of autism based on Kanner's criteria (although Lotter acknowledged that he did encounter individuals who did not exactly fit this picture), and that standardised instruments were not used in making the diagnoses. In a review of

more recent epidemiological studies that have tested larger samples using current diagnostic criteria and assessment instruments, Rutter (2005) concludes that most well-conducted epidemiological studies of autism spectrum disorders cite a prevalence of somewhere between 30 and 60 cases of autism spectrum disorder per 10 000 of the population. This figure is considerably higher than that reported in earlier epidemiological studies and is in part a reflection of the broadening of diagnostic criteria and improved methods for assessing these criteria. Whether this increase is a reflection of a true increase in incidence or of more effective diagnosis remains uncertain.

In addition to forcing us to revise our estimates of the incidence of ASD in the general population, the shift in conceptualisation from discrete entity to spectrum of conditions also prompts a reconsideration of their broader symptomatology. Symptoms need to be described in terms that are applicable to all manifestations of the spectrum. Such descriptions need to be sufficiently precise in order to enable all manifestations of the spectrum to be readily identifiable, but also because they form the starting point for many of the theoretical accounts that will be discussed later in this book. Furthermore, the revised prevalence estimates represent a shift in our thinking about the relationship between autism spectrum disorder and global intellectual disability. When the earlier prevalence figures were currently accepted, it was widely held that about 75% of individuals labelled autistic also had some degree of global intellectual impairment or mental retardation (Wing & Gould, 1979). However, with the shift to a broader, spectrum conceptualisation of autism, this proportion is estimated at about 25%, meaning that the majority of people with an autism spectrum diagnosis have normal levels of intellectual functioning.

The most striking feature of individuals from any part of the autism spectrum remains what Wing (Wing & Gould, 1979) refers to as social impairment. This can range from an almost total disconnectedness from other people, who are treated almost like pieces of furniture (so-called 'aloof' children), to those who passively accept the social overtures of others but rarely if ever initiate interaction and those whose behaviour consists of repetitive approaches centred on the individual's own concerns or obsessions rather than those of the person they are approaching ('active-but-odd'). More subtle interpersonal difficulties are often noted, such as insensitivity to the feelings of others or a failure to understand the reasons why people might act the way they do in certain situations. Attempts to explain social impairment have dominated research into ASD from the mid 1980s until the beginning of the present century and are dealt with in Chapters 2 and 3 of this book.

A second notable feature is the characteristic difficulty with imaginative and symbolic behaviours seen in individuals with ASD. We have already noted that since Kanner's first description, children with autistic disorder were described

as not playing with objects in the way typical children of similar developmental level do. Rather than pretend that one object is another (e.g. acting towards a brick as if it were a car or a boat), or acting out scenarios using miniature objects, they prefer to engage in repetitive and stereotyped object-related activities. Although older and more able children with ASD may develop some apparently symbolic routines with objects, these are often centred on one or two themes and repeated over and over again. Individuals with Asperger's syndrome often show little interest in more adult forms of imaginative activity such as fiction or televised drama, often reporting difficulties in following plots. More controlled observations have confirmed Kanner's initial observation (Baron-Cohen, 1987; Charman, Swettenham, Baron-Cohen, Cox et al., 1997; Wing, Gould, Yeates & Brierly, 1977; Wolff, 1985, see Jarrold, Boucher & Smith, 1993 for a review). Jordan (2003) observes that play is at once a transparently simple concept, yet one that is quite difficult to pin down in terms of precise and comprehensive definition. Behaviourally, it entails manipulation of objects in a way that is systematic yet flexible and that relates that object to some sort of context. The context is often social in nature, and much play in typical development occurs in social interactions, often with more able, older individuals, such as siblings or caregivers and, as we shall see in Chapter 2, psychological theories of social impairment closely link the development of the capacity to pretend with the ability to understand other people, especially the fact that other people have minds. Play, as has long been noted (see Piaget, 1962 and Vygotsky, 1962), has a symbolic component, in that attributes of the manipulated object, or, as in the example of using a brick as a car given above, another, absent object are evoked by means of relevant action sequences, which from Vygotsky's point of view, develop in a social context. Thus, impairments of play can result from difficulties with one or more of a number of components. There may be difficulties in imagining alternative uses for an object, or in evoking absent properties of an object (see Harris, 2000), or in the structuring of flexible action sequences (see Chapter 4 on impairments in executive functioning) or in social interaction.

Most of the studies that demonstrated impaired play in children with ASD nevertheless engage in some activity that could be coded as pretend or symbolic play, leading some researchers (such as Lewis & Boucher, 1995) to argue that given appropriate prompts, increased play activity could be induced in these children. In a review of the studies of prompting and play, Jarrold (2003) concludes that although some studies have demonstrated that children with ASD can be prompted to engage in pretend play, these children remain impaired in their overall level of play compared to matched comparison children. Jarrold also reviews studies that show that children with ASD are able to override the functional properties of props in a play scenario and use the props for a different purpose (e.g. using a pencil as a pretend toothbrush). The overall conclusion is that children with ASD can understand and produce

pretend acts but experience difficulty in organising these acts into more complex imaginative sequences. Jarrold also highlights a problem that is a recurring theme across almost all domains of psychological inquiry into ASD, namely that it is difficult to extrapolate from behavioural measures of play to the actual experience of the child who is playing. We need to be cautious drawing conclusions from task performance and when making inferences about underlying capacities or mechanisms.

Impaired symbolic and play behaviours seem to be related to impairments in the ability to generate novel approaches to solving problems. Such impairment tends to lead to repeated attempts to use unsuccessful strategies, giving the appearance of a repetitive behavioural repertoire. Repetitive behaviour constitutes one of the core diagnostic features of ASD and, like other features, manifests itself differently depending on the context of the wider symptomatology, especially level of overall cognitive ability. Together, impaired imagination and generativity coupled with a tendency to engage in repetitive behaviour has led to developments of accounts of ASD in terms of impairments in the so-called *executive functions*. These accounts will be explored in greater detail in Chapter 4.

Kanner's original account gives us a picture of language that is sometimes absent and often delayed in its development. When it does develop, it has the characteristic qualities of immediate or delayed echolalia and pronominal reversal. But these characteristics tend to be found in individuals who fit the Kanner picture and who have some degree of global intellectual impairment. Language impairments in people with ASD who are not globally cognitively impaired tend to be subtler and may relate more to their social impairments rather than language difficulties *per se*. We have already seen that Asperger observed that his patients had odd intonation and a tendency to engage in monologues about their specific interests. And more controlled investigations have discovered difficulties in organising discourse and in generating coherent narratives. For example, Losh and Capps (2003) compared the performance of children with high-functioning ASD (including some with a diagnosis of Asperger disorder) and matched typical children on a range of narrative tasks including personal and picture-book-based narratives. Although there were many similarities between the groups on measures such as length of narrative and numbers of personal narratives, the ASD group showed less thematic integration and coherence in their accounts, especially of their own personal experience. Whereas earlier studies of narrative production in more globally impaired children with ASD tended to show impairments in narrative length and numbers of narratives produced (see Tager-Flusberg, 1995), Losh and Capps' findings seem to suggest that even in the absence of global cognitive impairment, individuals with autism experience difficulties in organising their recall of experience in a way that enables them to provide a coherent account of it. This is a theme that will be taken up in the discussion of memory in Chapter 7.

## DIAGNOSTIC SYSTEMS AND INSTRUMENTS

It was not until 1980 that autism-related conditions were included in the third revision of the *Diagnostic and Statistical Manual* of the American Psychiatric Association (DSM-III, American Psychiatric Association, 1980), which included a category of *infantile autism*, later changed to *autistic disorder* in the revised DSM-IV (American Psychiatric Association, 1987). Since then, the shift in the conceptualisation of autism from a single entity to a spectrum of related conditions has been reflected in later revisions of this manual as well as in the procedures employed to make diagnoses. The current reference for diagnosing autism spectrum disorder is the text revision of the fourth version of DSM (DSM-IV TR, American Psychiatric Association, 2000), which, under the heading *Disorders usually first diagnosed in infancy, childhood or adolescence*, lists the category of *Pervasive Developmental Disorders* (PDD), which includes the conditions listed in Box 1.2. Inspection of this table shows that 'autism' consists of not one but a range of conditions that are assumed to be linked in some way. This immediately poses a problem: what terms do we use to describe the set of conditions set out in Box 1.2? Describing the individual elements is less problematic, in that the DSM-IV TR terms can be used, but choice of a collective term is more difficult. One possibility would be to opt for the DSM-IV TR term of PDD. But, although this may well (and probably should) become the case in the medium to long term, terms such as 'autism', 'autism spectrum' and 'autistic (or autism) spectrum disorder' have become so entrenched in the literature that changing terminology at this stage might be more confusing than enlightening. Moreover, using a term like PDD to cover all the conditions listed in Box 1.2 might confuse some readers into thinking that what was being referred to was pervasive developmental disorder not otherwise specified (PDD-NOS), which, because it is grouped along with atypical autism, gives the impression that it applies to atypical rather than typical manifestations. Because this book deals primarily with autistic disorder, Asperger disorder and PDD-NOS, I have decided to use the term *autism spectrum disorder* (usually abbreviated to ASD) when speaking of these conditions collectively. On occasions, especially where the literature under discussion warrants it, I use the term *autism* to refer to autistic disorder that is accompanied by some degree of global intellectual disability and *high-functioning autism* when no global disability is present. Because the term 'autism' has been used to describe a set of conditions as well as a set of symptoms, it will sometimes be used here to refer to the cluster of symptoms that are thought to underlie all manifestations of the autism spectrum. The terms *Asperger's syndrome* and *Asperger disorder* are used synonymously. In relation to the nomenclature of individuals (whether with autism or without) whose global level of development lags behind that of their age peers, the term *intellectual disability* is used, although on occasions where the research being described uses terms such as 'mental handicap', 'mental retardation' or 'global

cognitive impairment', then these are also used. All these terms are treated as synonyms.

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**Box 1.2.** Conditions listed under the heading Pervasive Developmental Disorders in the DSM-IV TR (American Psychiatric Association, 2000)

- Autistic disorder
- Rett's disorder
- Childhood disintegrative disorder
- Asperger's disorder
- Pervasive developmental disorder not otherwise specified (including atypical autism)

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The criteria listed in DSM-IV TR to determine whether an individual can be said to have autistic disorder or Asperger's syndrome are set out in Box 1.3. Inspection of the table shows that the key impairments in both conditions occur in the domains of social interaction and the flexible patterning of behaviour, reflecting the initial clinical descriptions of Kanner and Asperger. The major distinction between the two conditions on these criteria lies in the domains of communication, general cognitive delay and imaginative activities. For a diagnosis of autism, there must be evidence that at least one of social interaction, communicative use of language and symbolic or imaginative play were impaired before the age of 3 years, but there is no requirement for impaired communication or for general cognitive delay in order to make a diagnosis of Asperger disorder. Indeed, on these criteria such a diagnosis is reserved for those who show no clinically significant delay in language. In addition to the criteria for these two disorders, DSM-IV also allows for a diagnosis of PDD-NOS, which is characterised by a 'severe and pervasive impairment in the development of reciprocal social interaction . . .'. This may be accompanied by other features similar to those described for autism and Asperger disorder, but to an extent insufficient to meet the criteria for these and a range of other conditions.

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**Box 1.3.** DSM-IV TR diagnostic criteria

**Autistic disorder**

A A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
  (1) qualitative impairment in social interaction, as manifested by at least two of the following:

    (a) marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

    (b) failure to develop peer relationships appropriate to developmental level

    (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest)

    (d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

    (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)

    (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

    (c) stereotyped and repetitive use of language or idiosyncratic language

    (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

    (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

    (b) apparently inflexible adherence to specific, non-functional routines or rituals

    (c) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)

    (d) persistent preoccupation with parts of objects

B Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C The disturbance is not better accounted for by Rett's disorder or childhood disintegrative disorder.

### Asperger's disorder

A Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple non-verbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

    (2)  failure to develop peer relationships appropriate to developmental level

    (3)  a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)

    (4)  lack of social or emotional reciprocity

B  Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

    (1)  encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

    (2)  apparently inflexible adherence to specific, non-functional routines or rituals

    (3)  stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

    (4)  persistent preoccupation with parts of objects

C  The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D  There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years).

E  There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F  Criteria are not met for another specific pervasive developmental disorder or schizophrenia.

Although widely and increasingly employed, DSM-IV is not the only diagnostic system that has been used by clinicians or researchers. Another major framework is the tenth edition of the International Classification of Diseases (ICD-10; World Health Organization, 1993). The criteria used in this system show a remarkable similarity with those of DSM-IV. Other, less widely used criteria are those of Gillberg and colleagues (Ehlers & Gillberg, 1993), Szatmari, Bremner and Nagy (1989) and Wing (Wing & Gould, 1979), although they differ in certain respects, and although these differences have generated considerable debate (see Mayes, Calhoun & Crites, 2001), they share the notion that the core features of the condition hinge on impairments in reciprocal social interaction and the presence to some extent of repetitive behaviours of some kind.

The first observation to make about all the diagnostic schemes just described is that they specify *behavioural* criteria for the identification of ASD. Despite widespread consensus that ASD has a biological basis reflected in brain pathology, as yet there exist no biological or neurobiological markers to identify these conditions. Second, the criteria often refer not just to the presence or absence of particular behaviours but to their *patterning*. This patterning occurs both over the short term (i.e. that can be observed in a single encounter), such as repetitive or stereotyped activities, or over the longer term, such as atypical developmental trajectories in the area of social and communicative development. As a consequence of these two factors, any attempt at diagnosis must elicit evidence of behavioural indices for the diagnostic criteria and, where appropriate, their patterning over time.

Although the diagnostic systems themselves provide some indication of the kinds of behaviours to look for when deciding whether or not a diagnosis of ASD should be made, the descriptions are vague and can only be interpreted in the context of training under the supervision of someone experienced in making such diagnoses. In order to bring some standardisation to the process of making the behavioural observations needed to make a diagnosis, a number of formal assessment instruments have been developed, the most widely used of which are the Autism Diagnostic Interview – Revised (ADI-R, Lord, Rutter & Le Couteur, 1994; LeCouteur, Lord & Rutter, 2003) and the Autism Diagnostic Observation Schedule (ADOS-G, Lord, Risi, Lambrecht et al., 2000). Other instruments, such as the Childhood Autism Rating Scale (CARS; Schopler, Reichler & Renner, 1986) or the Diagnostic Interview for Social and Communicative Disorders (DISCO; Wing, Leekam, Libby et al., 2002) and the Developmental, Dimensional and Diagnostic Interview (3di; Skuse, Warrington, Bishop et al., 2004) also exist, the last two share with the ADI and the ADOS the requirement that users undergo formal training. Systems such as ADI, ADOS, DISCO or 3di represent codifications and standardisations of good clinical diagnostic practice. As such, they build on, rather than completely supersede, methods of diagnosis that have been used in the past and are to some extent still widespread. The purpose of all these instruments is to provide descriptions of the behaviours that need to be present to make a diagnosis of ASD, as well as to specify standardised methods for assessing the presence of these behaviours. The purpose of training is to ensure that the person using the instruments can make reliable and valid evaluations of whether or not specific behaviours are or have been exhibited and whether or not the diagnostic criteria are met. The process of making a diagnosis involves a trained observer recognising a particular pattern of symptoms. This implies that the observer must have encountered similar patterns in the past and, with the guidance of a trained supervisor, learn to distinguish them from other, similar patterns. It is this pattern-recognition process that is at the heart of the diagnostic process (for any condition, not just for autism) and it can only be mastered by exposure to a range of patterns that do and do not fit the

diagnostic entity of interest. This exposure to actual cases is at the heart of the process and is not made redundant by the use of more explicit procedures such as those embodied in the ADI or other measures. All that these measures do is to make explicit the criteria on which a particular diagnosis has been made and the manner in which those criteria were assessed with the overall aim of giving us greater confidence when comparing findings across different investigations that the participants in those investigations are similar in terms of their symptomatology. This point is important when we come to compare studies that have recruited participants using different diagnostic systems and different methods of assessment for diagnosis. It is always possible that participants in a study who were described merely as having 'a diagnosis of Asperger's syndrome' may not be directly comparable to those who 'met DSM-IV criteria for Asperger disorder on the basis of the ADI', although, as we shall see, it is likely that the latter are a subset of the former. But it is perhaps going too far to suggest, as does Mottron (2004, p. 21) that the findings of all investigations conducted before the advent of instruments like the ADI or the ADOS are unreliable because the diagnostic criteria and assessment processes used were not clearly specified, and threfore we can have no confidence in whether or not the participants did in fact have the disorder claimed by the investigator. The utilisation of a standardised instrument does not guarantee that the procedures and criteria specified by that instrument have been rigorously applied, any more than the non-use of such an instrument implies that they have not.

## DIMENSIONS VERSUS ENTITIES: 'LUMPING' VERSUS 'SPLITTING'

Despite the widespread acceptance of the existence of an autism spectrum comprising a range of different conditions, the historical legacy of the two original clinical accounts remains, fuelling a debate about whether the syndrome described by Asperger is a qualitatively different psychopathological condition from that described by Kanner, especially when the latter is not accompanied by global intellectual impairment. Moreover, current diagnostic schemes tend to encourage the assigning of individuals to categories, rather than thinking of dimensions of impairment. These two processes have contributed to the question of whether or not we should lump the different conditions from the autism spectrum together under a common heading or split them under different ones. This is a question that needs to be tackled both at a conceptual and an empirical level. Conceptually, we need to ask what we are trying to achieve by having a diagnostic system. The purpose of any diagnostic and classification system is to reduce the complexity and diversity encountered in clinical practice into a smaller set of categories, the members of which have features in common and who do not share features with members of other categories. So, for example, people who complain of abdominal pain can

be divided into those who have upper abdominal pain and lower abdominal pain, and each of these categories can be further subdivided, so that we eventually speak of inflammation of the stomach or inflammation of the appendix, each of which will have a set of symptoms that does not overlap with the other, and which will call for a different treatment strategy. The important point here is that the different symptoms actually do reflect different disease processes. In the context of abdominal pain, it is possible to draw up symptom sets that do not do this. If we were, for example, to have a scale of severity of pain, then this would not distinguish between stomach and appendix disease, since both can produce pain that is mild or severe. Patients could be reliably classified on this dimension, but whether this would be clinically useful, or whether it would tell us anything about the underlying reality of their disease would be questionable. In the context of diagnosing autism or Asperger disorder, we need to determine whether or not the differentiations required by DSM-IV or ICD-10 reflect different underlying dysfunctions. This is a question that can only be tested empirically.

Macintosh and Dissanayake (2004) identify two broad strategies for empirically determining whether Asperger's syndrome can be differentiated from high-functioning autism. The first is to take a large group of individuals and administer a number of measures, including a diagnostic assessment such as one of those described earlier on in this chapter. Cluster analysis is then applied to the data in order to see first whether subgroups of individuals can be identified, and then to see how these subgroups map onto the categories generated by the diagnostic system. For example, Prior, Eisenmajer, Leekam, Wing et al. (1998) applied cluster analysis to a group of 135 individuals who had been given a diagnosis of high-functioning autism, Asperger's syndrome or PDD according to DSM-III (an earlier version of DSM-IV) criteria. Measures used in the cluster analysis came from a questionnaire measure, the Autism Spectrum Disorders Checklist (Rapin, 1996) from which measures of social impairment, impairments in communication and imagination and repetitive behaviours were derived. Application of cluster analysis yielded three clusters (which they labelled A, B and C), with a majority of individuals (46%) with a diagnosis falling into cluster A, a majority of those with a diagnosis of Asperger's syndrome (58%) falling in cluster B and a majority of those with another PDD (56%) falling in cluster C. Prior et al. conclude from these observations that although the characteristics measured by the checklist they use do cluster into groups that resemble the DSM-based diagnostic categories, there is considerable overflow across the boundaries of these categories. In each of the three empirically derived clusters, almost half the participants came from one or other of the non-majority diagnosis for that group. Prior et al. argue that such observations support a spectrum view of ASD, which sees impairment as occurring along a number of dimensions, each of which may be impaired independently of the others.

The notion of a spectrum reflecting different dimensions of behaviour that can be independently impaired to a greater or lesser extent, with the

resulting cluster of impairments defining the clinical picture presented by the individual is seductive. However, such a conceptualisation begs a number of questions. First, how do we define what the dimensions of behaviour are? In Prior et al.'s study, they were derived from the Autism Spectrum Disorders Checklist, which as we have seen, seeks information about behaviours in the domains of social interaction, communication and imagination, and repetitive activities. But such a framework makes the questionable assumption that these dimensions are independent. There may well be, for example, a relation between repetitive behaviours and lack of imaginative activities (someone who is compelled in some way to repeat actions over and over may thus be prevented from engaging in more flexible behaviours that marks the existence of an imaginative capacity and help its further development). In short, we need a theory of what the dimensions mean and of what psychological processes might underlie their behavioural manifestations. Nevertheless, the approach of studies such as that of Prior et al. (1998) marks an important step in helping us to do just that. By showing that individuals can vary along behavioural dimensions that can be measured reliably, we have a basis for exploring underlying processes that goes beyond simple group classification. This process will be aided by the development of assessment instruments such as the 3di (Skuse et al., 2004), which provide quantitative estimates along dimensions of impairment as well as assignment of cases to diagnostic categories.

Macintosh and Dissanayake (2004) take issue with clustering studies for a number of reasons other than those just outlined. They identify several flaws in the sampling of some of the investigations that have used this method. For example, they argue that as the children who were diagnosed with Asperger's syndrome in the Prior et al. (1998) study also met criteria for autism, we cannot be certain whether the claimed qualitative similarity between the two conditions is not an artefact of poor sample selection. By labelling at the outset children with autism as Asperger children, it is perhaps not surprising that the cluster analysis came up with clusters that were quantitatively but not qualitatively different. Macintosh and Dissanayake further argue that cluster analysis ends up in assigning individuals to clusters in ways that can yield groups that are not matched on chronological or mental age, making it likely that the differences between the groups may be a result of differences on these measures rather than on more directly autism-related measures. However, this last point is valid only if the resultant clusters do differ on these measures, and even then it would be necessary to show that the differences were in a range of magnitude that was in some way related (either conceptually or on the basis of empirical evidence) to autistic symptomatology.

A second way to address the question of whether the different categories of ASD should be thought of as a single entity or several different entities is to recruit groups of people who meet criteria for the different subgroups and who are carefully matched on a number of variables such as IQ and age. These individuals are then tested on a range of measures that do not form part of