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Girls and Autism
Educational, Family and Personal Perspectives
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Autism
A New Introduction to Psychological Theory and Current Debate
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Autism Awareness Week 2019
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Where are all the autistic girls? An introduction

Barry Carpenter, Francesca Happé and Jo Egerton

Where are all the autistic girls? According to the UK’s National Autistic Society (NAS), one child in every 100 has autism, and 70% of those are educated in mainstream schools (National Autistic Society 2013). A diagnosis of autism spectrum disorder (ASD) is based on core behaviours appearing in early development (usually before three years of age): impaired development in social interaction and communication, and restricted and repetitive interests and activities (American Psychiatric Association 2013; Wing and Gould 1979). Although behavioural-cognitive traits associated with autism are found in the general population, it is the quality, intensity and co-occurrence that lead to a diagnosis when, together, these traits are impairing in everyday life (Lai et al. 2013). Until recently, there was thought to be a large gender gap in autism, with the ratio of boys to girls widely accepted as at least 4:1 (Dworzynski et al. 2012). However, researchers now propose a gender ratio in autism that is closer to 2:1 boys to girls (Zwaigenbaum et al. 2012).

Existing screening and diagnostic criteria have largely developed from Kanner’s and Asperger’s observations of autistic boys in the 1930s and 40s (Kanner 1943; Asperger 1991; Frith 1991; Silverman 2015; Wing 1981) and may lack validity when diagnosing girls (Cheslack-Potava and Jordan-Young 2012; Rivet and Matson 2011). There is some evidence of a gender-bias (Dworzynski et al. 2012; Gould and Ashton-Smith 2012); girls on the autism spectrum are typically diagnosed later and with more extreme behaviours than autistic boys, and those girls without additional intellectual or behavioural problems are likely to ‘fly under the radar’ (Dworzynski et al. 2012; Egerton et al. 2016).

In 2012, the NAS surveyed more than 8,000 people on the autism spectrum and their family members in the UK. They found that 41% of autistic females (compared with 30% of autistic males) had experienced misdiagnosis and were less likely to be given access to extra support. Only 8% of intellectually able autistic girls under six years (compared with 25% of boys) were diagnosed, rising to 20% and 50% respectively by the age of 11 years (Bancroft et al. 2012; Clark 2016). Nicola Clark, an autistic woman diagnosed in her forties, writes:

Many women remain undiagnosed until their 20s or 30s ... If a woman has had children, is in a relationship, is interested in makeup, music, fashion, or in my case doing stand-up comedy, this level of sophistication apparently makes diagnosis ‘less clear-cut’. At worst, it apparently makes autism seem ‘nonexistent’.

(Clark 2016)
Almost every professional in the education, health and care sectors will work with children on the autism spectrum at some point during their career. While many will be aware of the behavioural profile traditionally associated with the male-oriented diagnostic criteria, psychologists and psychiatrists are now suggesting that many girls do not fit this profile (Happé et al. 2006). In mainstream schools, for example, girls on the autism spectrum are frequently misunderstood or overlooked for support, especially if they have intellectual functioning in the average range. As Baldwin and Costley (2016) observe, ‘the absence of ID [intellectual disability] does not equate to an absence of learning support needs’.

Many autistic girls have a desire to fit in with their peers. It appears that, to a greater extent than most autistic boys, many girls use protective and compensatory factors to give the appearance of social conformity and integration with their peer group. They may use observational learning to interpret and imitate facial expressions, create scripts for social interaction and apply rules by rote to social-emotional situations and friendships (Tierney et al. 2016).

Girls’ repetitive and restrictive interests, while having the classic autistic intensity and duration, tend to be gender-influenced – the ‘little professor’ approach but applied to pop stars, boys, pets and fashion, for example. As Sarah Wild, head teacher of Limpfield Grange School for girls with communication and interaction difficulties, states:

> Just because the girls aren’t obsessed with Thomas the Tank Engine and lining things up in neat rows doesn’t mean they are not on the spectrum. Just because they can make eye contact, have a reciprocal conversation with someone for five minutes and exchange small pleasantries doesn’t mean they are not autistic. It means they’ve learned to do it. We have to redefine what we think autism is.

(Lee-Potter 2016)

Autistic girls’ education is also at risk unless they receive appropriate support or reasonable adjustments for their autism (Baldwin and Costley 2016). Unable to cope with the unrealistic expectations and demands of the school environment, unsupported girls on the autism spectrum may become school refusers or exhibit behaviours that lead to school exclusion (Sproston et al. 2017). Others become the quiet, anxious girl at the back of the classroom, concealing their difficulties behind a socially acceptable mask (Tierney et al. 2016).

For many autistic boys, their autism is externally expressed (e.g. in conduct disorders); however, autistic girls seem more likely to conceal and internalize difficulties. Over time, this imposes a detrimental psychological burden, making autistic girls vulnerable to emotional difficulties and to mental health disorders such as anxiety, self-harm, depressive, personality, and eating disorders (Baldwin and Costley 2016; Hull et al. 2017; Rubenstein et al. 2015). There are growing indications that autism may be an underlying cause for a significant number of undiagnosed girls experiencing these difficulties.

Currently, many professionals do not have sufficient awareness or knowledge of autistic girls to consider or identify autism as a possible cause of mental health or behavioural issues. Girls with undiagnosed autism and their families may receive blame, censure and exclusion instead of support. The strategies adopted to address their issues may be inappropriate and, at worst, have catastrophic lifelong impacts.

Professionals need new information to better understand girls on the autism spectrum, enabling them to recognize, understand, refer, support and teach autistic girls effectively.
To avoid bleak outcomes, autistic girls need a timely diagnosis, followed by an in-depth needs assessment leading to relevant, personalized interventions in the areas of education, social skills and relationships. Without this scaffolding, these girls are in danger of growing up to be women who remain ‘undiagnosed, without employment, hav[ing] no social contacts outside the family and … almost wholly dependent on their parents to support them in everyday living’ (Gould and Ashton-Smith 2012).

In the following chapters, autistic girls and women, their families, and professionals from a range of disciplines offer insights, knowledge and strategies from their lived experiences and professional perspectives to enable those living or working with girls on the autism spectrum in educational environments to provide more informed and effective support to these girls and their families.

**Overview of chapters in this book**

*Girls and Autism* is presented in five parts, contextualized by Chapter 2, ‘What does research tell us about girls on the autism spectrum?’. In that chapter, Francesca Happé, professor of cognitive neuroscience at King’s College London, reviews what we do, do not and must know about girls on the autism spectrum based on the latest research findings. She considers male-to-female ratios in autism and contemplates a ‘missing’ population of autistic girls and women which has been overlooked by traditional diagnostic interpretations. She discusses the male-biased stereotypes and diagnostic overshadowing that can result in misdiagnosis, late diagnosis or lack of diagnosis for autistic girls and women, and the implications for girls’ mental health and educational needs as they develop within a neurotypically oriented world.

Following Parts I and II, the part-title pages for, Parts III–V include insights from girls on the autism spectrum at Limpsfield Grange School, a residential secondary special school in the UK for girls with social communication and interaction needs, many of whom have an ASD diagnosis.

**Part II: Girls and autism: The lived experience**

The chapters in Part II describe the experiences of autistic girls and their families from early life, through school to adulthood. Chapter 3 is written by Katie Buckingham, founder and director of the award-winning Altruist Enterprises. Diagnosed with Asperger syndrome at 16 years old, she describes her personal account of living with autism, mental health issues and her journey to discovering the advantages of the condition.

Chapter 4, by well-known broadcaster and Royal College of Medicine patient lead Carrie Grant, describes her family’s experiences, focusing on two of her daughters, who have autism spectrum diagnoses. She writes about their developmental differences, school experiences and the fight to get help; she writes about strategies, looking after yourself as a parent, and the great hope she and her husband have for their children.

In Chapter 5, Sarah Wild, head teacher of Limpsfield Grange School in Surrey – the only maintained special school for girls with communication and interaction difficulties in the UK – introduces the reflections on autism by Limpsfield Grange girls that are interleaved throughout the book.
Venessa Bobb, founder of A2ndvoice, run by parents and carers of autistic children and adults, and a National Autistic Society branch officer, is mother to three children on the autism spectrum, two of whom are girls, and only one of whom is diagnosed. In Chapter 6, Venessa reflects on bringing up her autistic children within her own community, and considers autism from a Black and Minority Ethnic (BAME) perspective.

Sharonne Horlock, a secondary academy SENCO and parent of a young autistic woman, writes in Chapter 7 about the need for school communities to know more about, understand, and recognize autism within girls, and to acknowledge that supportive strategies, embedded in whole school practices, are a corporate responsibility. She introduces strategies identified by female autistic students within a mainstream setting that can shape an autism-welcoming environment.

**Part III: Girls, autism and education**

In Part III, the chapters focus on education – from leadership perspectives and curriculum emphases to exclusion experiences. In Chapter 8, Rona Tutt, educational author, speaker and a former president of the National Association of Head Teachers (NAHT), situates autism in relation to recent SEND system reforms and considers the implications for education professionals supporting autistic girls. She focuses on how leaders in educational settings can use the reforms to improve the recognition of girls on the autism spectrum at all stages of education, and how schools can develop these girls’ well-being and sense of self-worth.

Sarah Wild, in Chapter 9, explores teaching approaches and strategies that can be used when educating autistic girls, and considers the importance of building a curriculum that enables their academic progress, communication, independence, positive mental health/emotional wellbeing and potential employment routes.

In Chapter 10, Jane Friswell, an international education consultant, author and director of SEND Consultancy, an enterprise established with young people with special educational needs and disabilities (SEND), discusses school exclusions and the emerging evidence of higher exclusion rates among autistic girls – both those with a diagnosis and those as yet unidentified – and how to ensure sympathetic and personalized inclusion of girls on the autism spectrum.

Ruth Fidler, an education consultant specializing in pathological demand avoidance (PDA), describes how PDA is increasingly becoming recognized as part of the autism spectrum. In Chapter 11, she explains the effective educational strategies which, while overlapping to a degree with those for other autistic students, require adaptations in style and a different dynamic in order to reduce anxiety around demand-associated loss of control, to achieve co-operation, to facilitate learning and to promote emotional wellbeing for girls with PDA.

**Part IV: Autism, adolescence and social networks**

This section focuses upon adolescence and identity in relation to sex, gender, friendships and mental health. In Chapter 12, Dr Meng-Chuan Lai, assistant professor at the Department of Psychiatry, University of Toronto, discusses the importance of neuroscience when considering autism, sex and gender. He considers the insights that neuroscience provides
into how and why autistic people process, experience and respond to social situations differently to their neurotypical peers, as well as the influence of gender on the brain.

In Chapter 13, Dr Tina Rae, a consultant educational and child psychologist, and Grace Hershey, an occupational therapist specializing in child and adolescent mental health, explore mental health difficulties in undiagnosed or misdiagnosed girls on the autism spectrum and their high risk for developing mental health problems such as self-harm, anxiety and eating disorders. The authors address the importance of mental health screening, therapeutic interventions, staff skills and sharing quality information to ensure that autistic girls receive essential and effective support.

In Chapter 14, ‘Friendships on the autistic spectrum’, Dr Felicity Sedgewick, a post-doctoral researcher at King’s College London, and Professor Liz Pellicano, Macquarie University, Australia, report on research into autistic girls’ experiences of friendship, what their friendships mean to them, what they look for in and expect from friends, and how their friendship models differ from those of neurotypical peers and autistic boys.

In Chapter 15, Gillian Loomes, teaching fellow in autism studies at the University of Birmingham, considers adolescence and sexuality among autistic girls and women, what they need to know in order to navigate and assimilate their own experiences, and how families and others can usefully support them. Her chapter situates first-hand autobiographical accounts in the broader contexts of social and political identities, identity construction and social world impacts.

**Part V: Autistic girls: Looking to the future**

Part V looks forward in development to adulthood, but also forward in time to when autistic girls and women will enjoy equity with their peers, taking their places as valued contributors within a neurodiverse society that endorses and accommodates their strengths and aspirations. In Chapter 16, ‘Girls for the future: transitions and employment’, Jo Egerton, schools research consultant, Helen Ellis, autistic advocate and member of the Westminster Autism Commission and the All Party Parliamentary Group on Autism (APPGA) advisory group, and Professor Barry Carpenter, Oxford Brookes University, draw upon literature and personal experiences to review post-secondary education and employment opportunities and their aspirational synergy for autistic girls and women. They explore how autistic girls, autistic women and neurotypical colleagues can deepen their understanding of one another’s needs to establish parity of esteem and progress collaboratively towards a mutually enabling working environment.

In Chapter 17, Sarah-Jane Critchley, international autism education consultant and author, discusses training, standards, competences and partnerships with respect to developing skills in the workforce. She focuses on building the effectiveness and confidence of professionals to work with girls on the autism spectrum and the knowledge to provide the girls with the tools they need within a competency-referenced, school-based training and support structure.

Rachel Townson, online training and development manager for the NAS and autistic self-advocate, and Carol Povey, director of the NAS Centre for Autism, ask in Chapter 18, ‘What is essential to ensure autistic women are able to take their rightful place in society; what alterations does society need to make; and how can we create a society of
acceptance rather than settling for awareness?’ They consider the received roles and expectations presented to autistic girls as they make the transition from child- to adulthood, and discuss how they can maintain their sense of integrity while negotiating obstacles to societal inclusion.

Finally, Dr Wenn Lawson, psychologist, lecturer, author and trans-guy, in his epilogue, ‘A call to action’, highlights the need for a rallying call on behalf of all autistic females, stating ‘Action needs to be relevant, and it needs to be now’. The epilogue focuses on areas of co-produced research (‘Nothing about us without us’). He addresses the need to educate clinicians and professionals, the need to educate all teachers/trainers in girl and women specifics, the need to address the mental health needs of this population, and the needs for post school education, employment and ongoing relationships.

We hope that this volume gives voice to the experiences, concerns, needs and hopes of autism girls; this long-overlooked, vulnerable and too-often silent group have so much to teach us, if we can learn to listen and to recognize their vital role in and contribution to a fair and neurodiverse society.

Notes

1 ‘Identity-first’ language is currently preferred by many autistic adults, in contrast to the ‘person-first’ language that many professionals feel more comfortable with; the strong feeling that autism is not something that can be removed from a person, not something one ‘has’, is respected here. Because different views exist, however, even in the autism community, both forms of language will be found in this book.

2 Throughout the book, chapter authors have used different, but evidence-based, statistical sources so the figures quoted may vary slightly according to the sources used.

References


When planning a book about social skills, it seemed at least sensible, if not essential, to devote a whole chapter to autism. I certainly do not claim to be an expert on Autism Spectrum Disorder (ASD), so I suppose I come to this chapter with some trepidation as there are so many amazing text books out there on this subject and some much better qualified people than me to write about autism. But due to the nature of my work in social skills, I have naturally accrued many years of experience working with children and adults with a diagnosis of autism and so a book about social skills would be incomplete in my mind without us considering the specific difficulties that can occur in autism.

However, in attempting to describe Autism Spectrum Disorder, it is important to start by saying that this chapter will never be fully comprehensive. In fact, maybe we should not necessarily strive to understand ‘what autism is’. Instead, as Dr Damian Milton says (www.autismeducationtrust.org.uk), maybe we should strive to understand the ‘autistic people’ we work with as well as we can, and to see this as an ongoing process and mutually respectful interaction. We may also want to think about terminology. Most text books use ‘autism spectrum disorder’ and ‘people with autism’ but this can be unpopular with some people. Some autistic people say that ‘they are not people who “just happen to have autism”’; it is not an appendage that can be separated from who we are as people, nor is it something shameful that has to be reduced to a sub-clause’ (Sainsbury, 2000, p. 12). But some don’t want the label to precede them, so would prefer to be seen as a person first and having autism, second. In this chapter, I have chosen to use ‘autistic people’ rather than ‘people with autism or ASD’ simply because this is what my autistic friends prefer. I apologise if you would have preferred me to write it the other way.

In this chapter, I will briefly explain social skills difficulties in relation to autism and I will also look at some of the theories that explain why social interaction is more difficult for an autistic child or adult.
A diagnosis of Autism Spectrum Disorder

Autism used to be considered to be an extremely rare ‘disorder’ that only affected a tiny proportion of the population; however, in recent decades the numbers of those diagnosed as being somewhere on the wider ‘autism spectrum’ has massively increased. The National Autistic Society (www.autism.org.uk) quotes Brugha et al. (2012) in saying that there are around 700,000 people on the autism spectrum in the UK, that’s more than 1 in 100, and if you include their families, autism is a part of daily life for 2.8 million people.

Autism is a relatively new ‘disorder’ and if you go back to the 1970s, the prevailing view was that autism was categorical: you either have it or you don’t. It was Dr Lorna Wing, a social psychiatrist and parent of a daughter with autism, who first argued that autism lay on a spectrum, and was therefore much more common than previously thought. As Tony Attwood (2016) says, ‘Autism is not achieved by personal choice, and does not come about as a response to a particular parenting style. The new-born infant who is subsequently diagnosed as having autism has a brain that is wired differently, not defectively’.

The first person to recognise that the child’s development and abilities are different is usually the mother, or primary care giver. They may observe that their child has:

- A tendency to avoid, or be confused or overwhelmed in, social situations.
- A possible motivation to socialise, but difficulty reading body language or social cues.
- Intense emotions.
- An unusual profile of language skills that can include language delay.
- Different interests to other children of the same age.
- Difficulty coping with unanticipated changes in routines and expectations.
- Sensitivity to specific sensory experiences.

A diagnosis of autism is mostly carried out by a multidisciplinary team and in May 2013 we saw a change in this with the publication of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association 2013). Autism Spectrum Disorder (ASD) now replaces the term ‘Pervasive Developmental Disorder’ and the term ‘Asperger’s syndrome’ has been replaced by the new diagnostic category of Autism Spectrum Disorder Level 1, without accompanying intellectual or language impairment. The rationale for this according to Attwood (2014) was that ASD should be ‘conceptualised as a dimensional rather than categorical concept’, although in reality, the term ‘Asperger’s syndrome’ will probably continue to be used informally by both clinicians and the general public. Indeed Attwood (2014) says that he now uses the term ASD Level 1 (Asperger’s Syndrome) so that everyone is clear.

In addition, this fifth edition of the DSM-5 has replaced the triad of impairment with only two essential features of ASD: firstly, the child (or adult) will experience ‘persistent deficits in social communication and social interaction’, and secondly, ‘restricted, repetitive patterns of behaviour, interests or activities’ (DSM-5, 2013). So, having a diagnosis of ASD means that the person will struggle at some level with social communication and social interaction from requiring some support (Level 1) to requiring substantial support (Level 3). This is often the most common and prominent feature and the one that we will describe in more detail in this chapter.

The DSM-5 breaks down the deficits in social communication and social interaction into three areas or ‘symptoms’ which are summarised in the following table:
1. Deficits in social-emotional reciprocity

‘Ranging . . . from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions’.

2. Deficits in nonverbal communicative behaviours used for social interaction

‘Ranging . . . 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 expression and nonverbal communication’.

3. Deficits in developing, maintaining and understanding relationships

‘Ranging . . . from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers’.

We therefore know that a diagnosis of ASD will mean that the person will have some difficulties in social communication and social interaction and that they will need a varying degree of support in this area. Wing (1996) describes four groups of individuals with ASD whose social interaction can be described as either ‘aloof’, ‘passive’, ‘active but odd’ or ‘stilted and over-formal’. However, there is no single definition of the social impairment, rather there is a range of difficulties that varies from one individual to another. As the quote goes: ‘If you’ve met one person with autism, you’ve met one person with autism’ (Dr Stephen Shore).

So what are the specific difficulties? Simon Baron-Cohen (2008) summarises these potential social difficulties as follows:

- Extreme lack of interest in other people.
- Atypical eye contact: either hardly making eye contact, or staring at you for too long.
- Invading your personal space.
- Lack of reciprocity (no turn taking, no dialogue, just monologue).
- Preferring to be alone.
- Difficulties anticipating how someone will feel or what they might think.
- Difficulties knowing how to react to another person’s behaviour.
- Difficulty reading other people’s emotional expressions, in their face or voice or posture.
- Difficulty accepting that there may be other perspectives, not just a single correct perspective.
Areas of difficulty for the person with ASD

In the following sections, we will look at six areas of difficulties that autistic people experience that can all have a direct impact on their social skills: social use of language, conversational skills, literal understanding of language, body language, prosody and relationships.

Social use of language or ‘pragmatics’

As we have seen in the previous chapters on nonverbal and verbal skills, our communication is much more complex than it seems at first glance. Most of our communication happens nonverbally (93%) and we have rules that govern our social use of language (often referred to as ‘pragmatics’). These social rules are generally ‘unwritten and unstated, complex, constantly changing, and affect most areas of social interaction’ (Patrick, 2008). We see these rules in our conversations – how to greet and say goodbye, and how and when to take your turn. We see them in our body language – how close can we stand to someone and where do we look? And we see them in our voices – how a change in tone can mean the opposite to what the words actually mean. And to make things even more difficult, these rules change from person to person, from situation to situation and from age to gender to status.

So, communication happens within a social context. It is not just the words that people choose to speak, but all the other messages that are sent. Much of our communication is indirect, implied by a look, a nod, a smile, a gesture, which is understood by most of us, but is difficult for the autistic person to pick up on. So, it is understood by everyone at a meeting that when the boss said ‘someone needs to do that today’ (looking at Bob with a raised eyebrow) that she means Bob should do it. But this is not clear to the autistic person. They will understand it as ‘someone needs to do that today’ and if they happen to be that person (Bob) they will probably not do it!

So, the skill of effective communication is complex for the autistic person. As Powell (2016) says, it ‘involves not only articulating one’s own thoughts, but at the same time having an awareness of what the other person is thinking, feeling and saying, and then linking it all together. This requires multiple channels of attention to be processing at the same time’.

The autistic person may therefore struggle to follow these social rules of language for several reasons. First, it is harder to read the intentions of someone else (I will talk about this later in the section on theory of mind), so they may struggle to understand what the other person is thinking and feeling if it is not explicitly said. Second, they may not know the rule (think about the eye contact rule in the chapter on the eyes and face). Third, they may know the rule, but then not understand the purpose of it or the contextual side to it (who you can hug, why you might hug, where and when you can hug, etc.). Finally, they may not see the purpose of the rule (they don’t need to say hello or goodbye, so don’t see the point of doing it).

The underlying assumption with this area is that the autistic person has difficulty in ‘reading’ social situations and that this will affect the reciprocity and the quality of the conversations. Tony Attwood (2014) describes two main ways in which people may behave as a result of this. The most conspicuous is a tendency to be withdrawn, shy and introspective in social situations, avoiding or minimizing participation or conversations. Second, they may actively seek out social engagement, but be conspicuously intrusive and intense, dominating the interaction and being unaware of social conventions such as personal space. In each of these there is an imbalance of social reciprocity. However, Attwood suggests that there is a third strategy for coping with these difficulties that is mostly (but not exclusively) used by girls with Asperger’s syndrome. They avidly observe and intellectually analyse social behaviour and will attempt to achieve reciprocal social interaction by imitation, using an observed and practised social
‘script’ which is based on intellectual analysis rather than intuition. In this way, they are able to express superficial social abilities that can make it harder to diagnose them with autism.

**Conversational skills**

‘Smooth, reciprocal conversations are often difficult’ (Powell, 2016). Conversations with an autistic person can include moments where there appears to be a breakdown in communication ‘transmission’ – they are deep in thought, deciding what to say, looking away – which can be disconcerting to the other person. There are also moments when the autistic person takes over the conversation, interrupts and talks over the other person, or changes the topic and speaks in monologues. They may fail to take notice of the listener and to allow them to join in – which can also naturally cause a communication breakdown. We may see difficulties at the following stages of a conversation:

**Starting and ending a conversation**

As we saw in Chapter 5 on conversational skills, there are quite complicated rules around greetings and farewells in a conversation and the autistic person may not follow these rules, either for starting or ending a conversation. They may initiate a conversation by not using any form of greeting, launching straight into a subject with a statement or a question. Or they may say ‘hello’ and then pause while wondering what to say next. They may start a conversation with what may seem to the listener as an irrelevant comment or question, failing to give the listener a ‘lead in’ to what they are thinking about. And they may also break a social or cultural code by striking up a conversation with a stranger in a supermarket by asking them a seemingly strange, personal or irrelevant question.

Similarly, they may struggle with ending a conversation. They may not use any closing statement at the end of a conversation, or they will say ‘goodbye’ and then stand awkwardly. They may also keep talking because either they want to finish what they needed to say, irrespective of the effect on the listener, or they will not know if the other person wants them to finish, so they carry on talking. This can all also apply to written correspondence, with emails being sent with no opening or closing remarks or even a signature (Patrick, 2008), or where there is no response at all, as they did not realise a response was expected or required by the other person.

**Maintaining the conversation**

Having started the conversation, the autistic person may struggle to maintain it for several reasons. Firstly, and maybe most importantly, they have difficulty in showing that they are listening. During a typical conversation, we like people to listen to us when we are speaking and there is an expectation that the person listening will show us they are listening by looking at us, nodding their head, and using appropriate facial expression and vocalisations. These signals are less apparent when in a conversation with an autistic person, which can lead them to appear rude or unsympathetic as we can assume they are not listening to us.

Once the conversation has begun, there can also appear to be no ‘off-switch’ and it only ends when the child or adult has finished their predetermined ‘script’. The autistic person usually appears unaware of the effect of the monologue on the listener as they struggle to read the nonverbal responses and to alter their responses according to the social context. So, if the clues are all there that the listener is bored or needs to get away but the autistic person does not see these, then they may continue to speak. This difficulty to read people and the context means that they may give too much or too little information as they are unsure of what the other person wants. The friendly lady at the bus stop may ask the question ‘how are you?’, but
she doesn’t really want to know how you really are! During the conversation there can be ‘a lack of recognition or appreciation of the context, social hierarchy and conventions, and little attempt to incorporate the other person’s comments, feelings or knowledge in the conversation’ (Attwood, 2007). This may also mean that some individuals may find it difficult to adapt their language for their audience, for example using lots of technical vocabulary that they use regularly but not having the awareness that the other person does not understand and/or is not interested. In contrast to engaging in a monologue, there can be times when the autistic person is reluctant to participate in a conversation at all, especially if the topic is not of interest.

They may also frequently change the topic, unaware that the logical link between the topics is not actually obvious to the listener. Such conversations or monologues can appear to be without any structure and lack coherence or relevance to the context. The listener is left wondering what the ultimate point of the story will be and also whether they will have an opportunity to contribute. With this type of conversation, there appears to be a ‘conspicuous lack of inclusive comments such as ‘what do you think of that suggestion?’ or ‘have you had a similar experience?’” (Attwood, 2007), which can leave the listener feeling frustrated or bewildered.

Patrick (2008) also says that changing topics in the middle of a conversation happens because the autistic person may struggle to maintain a topic for more than a few reciprocal back-and-forth cycles, resulting in the need to abruptly change the topic so they can maintain the conversation. They may jump from topic to topic, with no obvious link or ‘connecting comment’ such as ‘could I change the subject for a minute and tell you about . . .’, which can leave the listener confused and unsure of how to contribute.

Another example of impaired conversational skills is the difficulty of repairing a conversation. As we talked about in the chapter on conversations, it is important to seek clarification when something is unclear or confusing. This can be difficult for the autistic person to do as they may lack the confidence to say ‘I’m confused’ and may prefer to just change the topic to an easier one. In addition, when the listener is confused and seeks clarification from the autistic person, they can struggle to provide an explanation using other words and may just repeat the same ones with no added clarity.

Finally, we may see children and some adults seemingly talking to themselves, commenting on their own actions or giving a monologue without the need for a listener. They may do this for several reasons: to help figure something out and express themselves, to keep themselves company (and feel less lonely), or to rehearse possible conversations for the following day (Attwood, 2007). This can be a problem the following day when the conversation that has been played out and rehearsed carefully does not go the way they had planned when the other person says something unexpected!

I spent a few years working with a young lady called Jessie who told me how sometimes conversations didn’t go the way she had planned and gave me the following example:

**A conversation between Jess and Dan as described by Jessie**

**How I predicted it would go. . .**

Me: Hey, Danny, I got a new game today.
Danny: Awesome, what game was it?
Me: GTA which means grand theft auto.
Danny: Wow cool Jessie, I’ll have to see it next time I’m over.

**Danny:** That’s cool, Jessie, have you played it yet? What do you do on it? Is it good?

Me: Yes, I spent all day playing it and you can do loads of things from driving cars planes and helicopters around to doing missions. And yes it’s amazing.
Literal understanding of language

Language is used to send and receive messages that are both literal and figurative. The literal message uses words that are meant exactly as they are defined, so we say what we mean. These are nice and easy to understand for the autistic person, as there is no implied meaning or confusing imagery going on. Figurative messages, however, contain words that imply something else, not what the words necessarily mean, and we use these far more than we probably realise in everyday spoken language. We use figurative language to ‘create emphasis, amplify meaning, draw a comparison or contrast, or to make a rhetorical point’ (Sutcliffe, 2004). Examples of these are shown in the table below:

<table>
<thead>
<tr>
<th>Defined as</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similes</td>
<td>As light as a feather. As brave as a lion.</td>
</tr>
<tr>
<td>Metaphors</td>
<td>A recipe for disaster. All the world’s a stage. The light of my life. Broken heart. Bubbly personality.</td>
</tr>
<tr>
<td>Idioms</td>
<td>Over the moon. Break a leg. Grab a bite.</td>
</tr>
<tr>
<td>Puns</td>
<td>An elephant’s opinion carries a lot of weight. ‘On the contrary, Aunt Augusta, I’ve now realised for the first time in my life the vital Importance of Being Earnest.’ (Oscar Wilde)</td>
</tr>
<tr>
<td>Paradoxes</td>
<td>I am nobody. I can resist anything but temptation.</td>
</tr>
</tbody>
</table>
Autism Spectrum Disorder and social skills

<table>
<thead>
<tr>
<th>Defined as</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Irony</td>
<td>The use of words to convey a meaning that is the opposite of its literal meaning.</td>
</tr>
<tr>
<td></td>
<td>(I had to work all weekend) ’How nice!’ (But meant ‘how horrible!’).</td>
</tr>
<tr>
<td>Sarcasm</td>
<td>Is an ironic or satirical remark that seems to be praising someone or something but is really taunting or cutting. It often depends on the tone of voice.</td>
</tr>
<tr>
<td></td>
<td>Oh, I love you! (with tone of voice that would indicate that they don’t love you). That’s just what we need! (not).</td>
</tr>
<tr>
<td>Parables</td>
<td>A short story that uses familiar events to illustrate a religious or ethical point or conveys a meaning indirectly by the use of a comparison, or an analogy.</td>
</tr>
<tr>
<td></td>
<td>The boy who cried wolf.</td>
</tr>
</tbody>
</table>

Understanding figurative speech is often hard, especially for the autistic person, as it requires us to identify subtle relationships between words and phrases, and then understand the meaning from the message based on our prior experience (or knowledge) rather than direct observation, and then finally to take the perspective of the speaker. Sarcasm in particular requires us to know the speaker well enough to know if his message is reliable or not. How often have you said, ‘are you joking?’ So sometimes we get it wrong. So all of this can be very confusing for the autistic person and can lead to many misunderstandings within interactions as our language can appear illogical or untrue. It can also lead to the autistic person responding to something in an unexpected way. I work with a speech and language therapist (speech pathologist) who was once working with someone on recognising facial expression. She made her face look angry and asked the person how she looked and the response was ‘ugly’. We still smile about that session!

Body language

This is another distinct characteristic of autism. As we saw in the DSM-5 criteria, a deficit in nonverbal communication is a symptom and is defined as ‘ranging . . . 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 expression and nonverbal communication’ (American Psychiatric Association, 2013). A description of ‘clumsy or gauche’ body language is also included in the diagnostic criteria for Asperger’s Syndrome by Christopher Gillberg (Gillberg and Gillberg, 1989). This means that we will often see difficulties in all aspects of body language, including use of eye contact, facial expression, gesture, distance, touch, posture and fidgeting.

Eye contact

It is common to see difficulties with eye contact in autistic people. They may avoid eye contact all together or stare. Or they may look at other parts of the face or body, such as the mouth. Research by Klin et al. (cited by Attwood, 2007) found that autistic adults tend to look less at the eyes and more at the mouth, body and objects. If you ask an autistic person why they find it difficult to look at the other person’s eyes, some may describe an uncomfortable feeling, and even pain, when trying to make eye contact.
Facial expression

Hans Asperger noted that some of the children he saw had unusual facial expressions, sometimes ‘sparse and rigid’ (cited by Attwood, 2007). There can be a lack of variation in facial movements to express thoughts and feelings, which gives them a flat facial expression, which then can make them appear sad. Attwood also describes how, when asked to make a particular facial expression, he has even observed children and adults physically manipulating their face to try to resemble that emotion, for example pulling their mouth down or up. One explanation given was that they cannot express what they are not feeling at that moment in time.

Body positioning

The autistic person often has an unnatural posture or gait, which can vary from rigid to exaggerated. They may be unsure of how to position themselves so as to appear part of a group, or how to stand to show another person they are part of the conversation, interested and engaged. This can then result in them appearing on the outside of group and social situations. They may also struggle with the appropriate use of hand gesture – either using no gesture or at times exaggerated, theatrical gesture. They will often stand too close and may touch the other person inappropriately during the conversation – for example, by putting a hand on their shoulder. Finally, they may fidget or remain very still.

In addition to the autistic person having difficulties in body language themselves, they also struggle to accurately interpret nonverbal communication of others. This leads to constant misunderstandings as our body language accounts for as much as 55% of the meaning in face to face communication. We all give nonverbal signals that signify to our listener that we are interested or bored, that we are happy or sad. So, if our listener is not able to read the nonverbal signals that indicate ‘I am bored now’ or ‘don’t talk to me now’, there is a lot that can go wrong that will seriously affect the success of social communication.

Prosody

As we saw in our previous chapter on listening and paralanguage, our communication is so much more than words alone and our paralanguage gives the listener important information about how we feel, what we want them to listen to, whether we are serious or joking, and whether we want them to answer us. When listening to the speech of an autistic person, we can often hear unusual patterns in their paralinguistic skills. Attwood (2007) cites research which has confirmed that the prosody of children and adults with ASD can be unusual, especially with regard to pragmatic prosody (where the change in speech draws attention to something – an opinion, thought, intention) and affective prosody (where it communicates feelings and attitudes). For some autistic people, there is a lack of variation in their intonation, volume and rate, which leaves the speech with a rather monotonous quality. For some people, their speech is too loud or has a high pitched nasal quality, which was first described by Hans Asperger. For some, their speech is dysfluent. And finally, some have adopted the accent of someone else, probably a character in a film, which may mean they speak in a foreign accent.

In addition to having difficulties with prosody, they may also have difficulty in understanding the relevance of paralanguage when listening to the speech of other people. This may mean that some individuals may misinterpret tone and think they are being shouted at
when someone uses a firm voice. As we have said, these subtle clues are extremely important to establish intent, thoughts and emotions, and the autistic person will need support to understand these. So we can look at the different words that are emphasised in the following sentence and come up with seven different meanings!

### ‘Stressed Eric’

‘I didn’t say you have smelly feet’

- I didn’t say you have smelly feet (but someone said it)
- I **didn’t** say you have smelly feet (I definitely didn’t say it)
- I didn’t **say** you have smelly feet (but I implied it)
- I didn’t say **you** have smelly feet (but someone does)
- I didn’t say you **have** smelly feet (but maybe you did)
- I didn’t say you have **smelly** feet (but I did say something about your feet)
- I didn’t say you have smelly **feet** (but you have something else that is smelly)

(‘Stressed Eric’ taken from Kelly, 2018)

### Relationships

Friendships and relationships are complicated, emotional and unpredictable, which makes them all very challenging for the autistic person. The DSM-5 defines deficits in developing, maintaining, and understanding relationships as one of the core symptoms of the persistent deficits in social communication and social interaction that someone with ASD experiences. This is defined in the DSM-5 as ‘ranging . . . from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers’ (American Psychiatric Association, 2013). There are a few issues that affect the autistic person from making and maintaining friends.

#### The need for friendship

The autistic person may not be motivated to make friends and may prefer the solitude of the library to the chaotic and noisy playground. And when they do want to ‘socialise’, they may seek out the company of adults to answer their questions rather than the other children who play games with incomprehensible rules. As Powell (2016) says, there is a ‘clash of culture between the autistic and neurotypical world over socialising’. People in the neurotypical world prioritise socialising and friendship above most other things. We know that our friends are good for us; they help to lower our stress, increase our self-esteem and support us to solve problems. But in the autistic world this is often not the case. Socialising does not come naturally and is often an effort and can be tiring. This brings us to the capacity for socialising.

#### Capacity for socialising

We all have different capacities for socialising. I am happy to see friends at the weekend, but my husband finds too much socialising tiring and so we have to compromise so that we are both happy. As a rule, autistic people feel more comfortable if social interactions are ‘brief, purposeful and have a fixed ending as they will need to go away and recharge their batteries’
Autism Spectrum Disorder and social skills

(Powell, 2016). Solitude is often a natural state for autistic people and can be an effective way to calm down and restore emotionally. As Powell (2016) says, someone with ASD may describe their capacity for socialising as ‘I fill up quickly . . . [and] after a while I’m used up, spent, I’ve said what I want to say and need a break, some restoration time, time on my own’. I have an autistic friend who I see once in a while. Our meetings are very enjoyable, but she likes to know at the beginning how long I am going to be there, and I have learnt that short meetings (usually no more than an hour) are just perfect. We chat, we laugh and then suddenly I am gone. And I know she is sat quietly in her flat, chilling out, restoring herself. Which bring us on to the next issue: two’s company, three’s a crowd.

**Two’s company, three’s a crowd**

Like my friend Jessie, autistic people can function reasonably well sometimes in a one-to-one social situation, but things get a lot more complicated when more people are around. The more people there are in a social situation, the more we have to try to understand and monitor an increasing number of relationships between those involved. For example, two people equals one relationship; three people equals three relationships; but four people equals six relationships. This means we are not just having to process the language and nonverbal communication of more people, but also each individual interaction and relationship.

This can all be made worse if the autistic person has slow processing and cannot keep up with the conversation. The other issue can be ‘small talk’. Autistic adults often say that they are poor at ‘small talk’ or ‘chit-chat’, or they may say that they have learnt to do it but don’t see the point. We usually engage in small talk to establish rapport or acknowledge the presence of someone, or simply for the pleasure of being friendly. We say ‘hi, how are you?’ to the person at the bus stop or the lady at the post office, but we don’t really expect them to answer truthfully. We talk endlessly about the weather: ‘bit chilly today isn’t it?’, but we don’t really want to discuss the weather in detail. We are just being friendly. There is no real purpose or defined goal and it is often pretty spontaneous. And all of these things make this hard for the autistic person.

**The motivation to have friends**

Autistic people have certain qualities that make them good friends and partners and there may be a desire to establish friendships. But there also may be an unrealistic idea of what friendship entails. Attwood (2014) describes a particular developmental sequence that children who have Asperger’s syndrome display.

- **In the early years**, the child may not be motivated to socialise with peers, having discovered that other aspects of life, such as collecting or reading about something, are more enjoyable than socialising. They may spend long periods of time in solitude, preferring to be engaged in their special interest.

- **In the early primary years**, the child may see other children having fun and will actively want to play with their peers. However, their level of social maturity is usually at least two years behind that of their peers, and they may have difficulties with the degree of reciprocal and cooperative play expected by other children. The play tends to be more active rather than conversational, with games that are simple and that have clear rules that must be followed. They may at this stage become acutely aware of being different and will want a friend to play with, as they long for social inclusion. But they are also not good in their judgements of which children are good to play with and which should
be avoided. For all these reasons, they are very vulnerable to ridicule, being bullied and
being rejected by their peers.

- **In adolescence**, relationships are more about having someone to confide in rather than
someone to play with, and the gap in social understanding becomes more apparent, as the
young autistic adult can be overwhelmed by the increasingly complex nature of friend-
ship, which can lead to isolation and loneliness. If they do achieve genuine friendships,
they can have a tendency to be too dominant or rigid in their view of friendship, which
can be an issue. But with a compassionate, sensitive child as a friend, or with a socially
isolated child who shares some of the interests of the autistic child, friendships can be suc-
cessful, if a bit functional and practical.

- **In adulthood**, some adults with Asperger's syndrome can succeed in achieving an inti-
mate, and possibly life-long, relationship, although they may come to this several years
later than their peers. Their partner usually has an understanding of ASD, either because
they share some characteristics or they are naturally compassionate in understanding their
autistic partner.

# Theories of ASD and how they affect social communication

Having described the specific difficulties pertaining to autism, we will now briefly describe
some of the key psychological theories that offer possible explanations for the social chal-
lenges in autism, and which may account for their different experiences of the social world.
These are important to understand, especially when teaching social skills. My experience is
that even though it may be relatively easy to teach someone a specific social skill, unless you
teach it within a context and develop their social understanding, it will be difficult for them
to put the skill into a social context appropriately and achieve social competence. To help us
with this, we are going to look at four theories of autism: theory of mind (ToM), weak central
coherence, empathising-systemising theory, and executive dysfunction theory.

## Theory of mind

One of the most enduring psychological theories concerning autism has been the assertion that
the key universal core ‘deficit’ found in autistic spectrum disorder is an impaired ‘theory of
mind’ (Baron-Cohen et al. 1985). However, as we will see later, it is not a popular theory with
everyone, especially with some autistic people, and it is certainly not helpful when we hear
sweeping statements such as ‘autistic people lack empathy because they have a lack of theory
of mind’. However, it is well researched and documented and deserves a thorough description.

The term ‘theory of mind’ (ToM) means the ability to recognise and understand thoughts,
beliefs, desires and intentions of other people in order to make sense of their behaviour and
predict what they are going to do next. It is also sometimes referred to as ‘mind reading’ or
‘mind blindness’ (Baron-Cohen, 2008), or more colloquially, ‘putting yourself in someone
else’s shoes’. A synonymous term is empathy (Gillberg, 2002). And as Attwood (2007) states:
‘the child or adult with ASD does not recognise or understand the cues that indicate the
thoughts or feelings of the other person at a level expected for someone of that age’.

So, when we see someone turn to look out of the window, we may infer that they have
seen something of interest, and that they may know something that we cannot presently see.
It might even be something that they want. Baron-Cohen (2008) says this is going beyond
‘mere behaviour to imagine a whole set of mental states that link up in the other person’s
mind’. When we mind read, we can not only make sense of another person’s behaviour (why did their head turn or their eyes move to the left?), but we can also predict what they might do next (if they like what they saw, they may move towards it or if not, move away).

We also use our ToM to identify someone’s intentions behind their gestures and speech. If we see someone look at someone else and then look at their watch, we can infer that one person is communicating to the other that it is time to leave. They want the other person to understand that by looking at their watch, they are actually saying ‘look at the time, it’s late, we had better go’. The autistic person, however, may just wonder why they looked at their watch and may not infer the actual meaning behind the message.

It is in this sense that theory of mind can be thought of as a theory: it explains and predicts others’ behaviour. The theory proposes that autistic children are delayed in the development of their ToM, leaving them with degrees of ‘mind blindness’. As a result, they find it much harder to interpret or anticipate what others are doing or are going to do, and as a consequence will be puzzled, or even frightened, by the other person’s ‘unpredictable’ behaviour.

Baron-Cohen (2008) identifies the key stages in the typical development of theory of mind which are summarised in the table below:

<table>
<thead>
<tr>
<th>Age</th>
<th>A neurotypical child</th>
<th>An autistic child</th>
</tr>
</thead>
<tbody>
<tr>
<td>14-month-old</td>
<td>Child shows <em>joint attention</em> (such as pointing or following another person’s gaze) and pays attention to what the other person is interested in.</td>
<td>Child shows reduced frequency of <em>joint attention</em>. They point less, look at faces less and do not turn to follow another person’s gaze as much as a neurotypical child.</td>
</tr>
<tr>
<td>24-month-old</td>
<td>Child can engage in <em>pretend play</em>. They begin to use their mind reading skills to understand that in the other person’s mind, they are pretending.</td>
<td>Child shows less pretend play, or pretence is limited to more rule-based formats, such as a script from a film.</td>
</tr>
<tr>
<td>3-year-old</td>
<td>Can pass the <em>seeing leads to knowing test</em>. This means that when shown a picture of two children and a box, they identify the child looking in the box as the one who knows what is in a box (as opposed to the child touching the box).</td>
<td>The child is delayed in passing this test and is unable to do it at this age. They often need to be taught this specifically and will not pick it up naturally by interacting in the social world.</td>
</tr>
<tr>
<td>4-year-old</td>
<td>Can pass the <em>false belief</em> test where children are told the Sally and Anne story: Sally hides her marble in a box but when she goes out of the room, Anne moves the marble to the basket. The child is asked where Sally will look for the marble when she comes back in the room. The child will say that Sally will look for it in the box, since this is Sally’s <em>false belief</em>.</td>
<td>Most children say that Sally will look where the marble actually is (in the basket), even though there is no way she could have known it had moved. In this way they demonstrate that they are unable to take another person’s point of view.</td>
</tr>
</tbody>
</table>
Deception is easily understood at this age and they may attempt to deceive others. This is a sign of normal ToM, as it involves manipulating someone else’s mind to make them believe that something is true when it is not.

The child is capable of understanding more complex second-order mindreading. For example, in the Sally-Anne test, Sally may peek through the keyhole and see where Anne has moved the marble (Anne thinks that Sally doesn’t know she has moved the marble).

The child is capable of figuring out what might hurt someone else’s feelings and what might be better left unspoken, i.e. they can recognise faux pas.

A 9-year-old can also interpret another person’s expressions from their eyes to figure out what they may be thinking or feeling.

The autistic child is delayed by around three years in this skill and do not show this until they are 12.

Table 11.4 (Continued)

The relevance of a delayed ToM on a person’s social competence is significant. If someone has difficulty taking the perspective of another person, they are more likely to be puzzled by the actions of others, have difficulty recognising and working out the feelings of others and are likely to find people unpredictable. If someone is not able to ‘read’ someone else, they are more likely to encounter misunderstandings and may have more difficulties resolving conflict and showing empathy. A delayed ToM will also mean that autistic people will have ‘a one-channel, single, literal perspective of the world’ (Powell, 2016). So, they may take things very literally as they struggle to ‘read between the lines’. All of the above will lead to difficulties with reciprocal interaction.

A further consequence of literal one-track thinking is that autistic people often have a strong sense of social justice, or moral code, and like to keep strictly to the rules. This in itself is not a bad thing. But it can cause problems, as they may lack negotiating skills and are likely to be rigid and confrontational in their approach. Finally, a delayed ToM will also mean that the autistic person is often remarkably honest and may not recognise the need to tell ‘a little white lie’ to avoid hurting someone’s feelings or cause offence. I currently work with a delightful young autistic man called Joe. I introduced Joe to our new male speech and language therapist, Chris, and his first comment to Chris was ‘you have very narrow shoulders for a man’. Of course, this is actually quite true – Chris has a narrow, slim build and therefore narrow shoulders, but it is not really what Chris wanted to hear on his first day at work!
This theory that autistic people have an impaired theory of mind has, however, been criticised. Eisenmajer and Prior (1991) state that failure on ToM tests could be due to difficulties in language processing or memory and DeGelder (1987) argues that it could be a lack of motivation to deceive. Some theorists question its applicability to all on the spectrum when 20% of children pass these tests, or its value for explaining all the aspects of what constitutes the autistic difference (Happe, 1994). It has also been argued that a deficit in ‘social functioning’ cannot be solely located within an individual, and that what is being seen as a ‘theory of mind deficit’ could be more to do with a breakdown in communication between two people who process information very differently. In this sense there exists a ‘double empathy problem’, as Damian Milton calls it, in that both autistic and neurotypical people have a severe difficulty in understanding each other, as neither shares the same frame of reference within social interactions (Milton, 2012). This is most evident by how empathetic autistic people seem to be if they share similarities with someone else. So, whereas this theory may help us to understand some of the underlying difficulties that an autistic person may experience, it is certainly not the whole picture.

**Weak central coherence**

This second theory suggests that ‘people on the autistic spectrum have problems in integrating information to make a coherent, global picture. Instead, they are said to focus on the small, local details in a scene’ (Baron-Cohen, 2008). This means that whereas the neurotypical mind has a strong central coherence and can attend to the gist of a scene rather than the nitty-gritty, the autistic mind is said to have weak central coherence and will attend to the detail and not see the whole picture.

This can mean that the autistic person is overwhelmed with the details of a scene: the sights, the sounds, the smells, the words that people are saying, and they may take longer to process the whole picture and make sense of what is happening. The autistic brain picks up on too many details, which is an advantage in maths or programming but, in everyday life, can be overwhelming. A common reaction to this overload is for the autistic person to try to control and order their lives: to systemise, break things down into categories, create a structure, routine and rituals, so that their world becomes more ordered and predictable. This sense of sameness generates a sense of safety and the establishment of a routine ensures that there is no opportunity for change, or the need to create a new coherence or framework to understand what is happening and what is expected of you.

This theory explains some of the aspects of autism that we have not discussed in this chapter, such as the islets of ability we may see in autism and the excellent attention to detail, memory and skills in a narrow topic. It can also explain why autistic people outperform non-autistic people in some visual tasks, such as ‘embedded figure tests’ and ‘block design’ tasks (Shah and Frith, 1993).

However, in relation to social contexts, this means that ‘they may not ‘see’ the whole ‘social picture’ and this may lead to inappropriate behaviour’ (Howley and Arnold, 2005) as they are missing some of the essential information. An example would be if an autistic person is sent to an office with a message for a colleague, but then does not ‘read’ their colleague’s facial expressions and gestures, which are saying they want them to wait as they are on the telephone. The autistic person does not see the whole social picture and may deliver the message regardless of the signals. This theory also explains why they may remember details within a story but not the overall gist of the narrative, and may then give irrelevant information or struggle to summarise the important points.
Empathising-systemising (E-S) theory

This theory is linked to the theory of mind hypothesis, but adds in the dimension of a superior skill: ‘systemising’. Professor Simon Baron-Cohen (2008) suggests that the two defining characteristics of autism are ‘empathising’ and ‘systemising’ and that these skills are opposite each other. The more empathy you have, the less systemising you have. Empathy encompasses not only ToM (cognitive empathy), but also the response element: having an appropriate emotional reaction to another person’s thoughts and feelings (affective empathy). Systemising is the drive to analyse or construct systems; when we systemise, we are trying to identify the rules that govern the system in order to predict how that system will behave, for example, a numerical system like a train timetable, or a collectible system like a collection of stones or stamps. People who are systemisers ask questions and want to know how things work. They may collect things or take things apart. They may study numerical systems or make lists of capital cities. They prefer predictability, repeat patterns and they resist change.

Baron-Cohen (2008) states that:

According to the empathising-systemising theory, autism and Asperger syndrome are best explained not just with reference to empathy (below average) but also with reference to a second psychological factor (systemising), which is either average or above average. So it is the discrepancy between E [empathy] and S [systemising] that determines if you are likely to develop autism or Asperger syndrome.

This is sometimes referred to as the ‘extreme male brain theory’, as Baron-Cohen’s research found clear sex differences between male and female brains. In brief he found that the male brains are better at systemising and female brains are better at empathising, and autistic people score higher than average males and females on systemising traits and lower on empathising. Seen in this light, autism can be conceptualised as an extreme of the typical male profile which was first put forward by Hans Asperger in 1944 (cited by Baron-Cohen, 2008).

The strength of this theory is that it is a two-factor theory, which can explain both the social and non-social features in autism. The below-average empathy can explain the social communication difficulties, whilst average or above average systemising is a way of explaining the narrow interests, repetitive behaviour and resistance to change or need for sameness.

Executive dysfunction theory

The psychological term ‘executive function’ is defined as the ‘ability to control actions’ (Baron-Cohen, 2008). It refers to the ‘ability to maintain an appropriate problem-solving strategy in order to attain a future goal’ (Damian Milton, www.autismeducationtrust.org.uk) and, according to Attwood (2008), this includes:

**Executive function**

| Organisational and planning abilities. | Time management and prioritising. |
| Working memory. | Understanding complex or abstract concepts. |
| Inhibition and impulse control. | Using new strategies. |
| Self-reflection and self-monitoring. |  |
Executive dysfunction is characteristic of patients who have suffered damage in the prefrontal cortex, and whilst in autism there has not been any damage to the frontal lobe, developmentally the prefrontal cortex may not have matured in the typical way. According to this theory, some of the core features of autism are best explained by an inability to plan actions (executive control) and shift attention, such as transitioning. So, autistic people may have difficulties with switching attention and may have an adverse reaction to interference with attention (Tammet, 2006). They may also struggle to inhibit a response, have problems with working memory and using new strategies, and may also struggle with organising and prioritising work, and with abstract reasoning.

However, there is also evidence that some autistic people have performed well on executive functioning tests. Dawson et al. (2007) found that autistic people can often do very well at nonverbal IQ tests and problem-solving tasks that do not require verbal processing. Damian Milton (www.autismeducationtrust.org.uk) summarises that this suggests that executive planning for nonverbal tasks is separable in brain functioning from verbal tasks, or that this weakness in verbal response tests is not due to an executive functioning deficit.

In terms of understanding social competence, this theory is possibly the least useful. However, it may help to explain some aspects, such as a tendency to monologue or difficulties with turn taking, and some difficulties inhibiting their own beliefs and thoughts. Also, it helps to explain the fact that they may struggle to draw and reflect on past social experiences in order to problem-solve, anticipate and remember rules in social situations, and to change their behaviour. But, out of the four theories, it probably explains more about difficulties within the domains of cognition, motor and repetition than in social interaction.

**Summary**

In this chapter, I have only focused on social communication in autism and so I would also recommend that the reader explores the difficulties relating to the other main area of deficit relating to restricted, repetitive patterns of behaviour, as this will also guide your intervention in other practical ways. I have found that the more I understand about autism, the more I am able to be successful in supporting the young people I work with who have a diagnosis of autism, so I am hoping that this goes some way to increase your understanding of why autistic people struggle with their social skills.

I am also aware that in writing this chapter, I may have focused on the ‘difficulties’ and ‘deficits’ of autism and, whereas I know this knowledge has helped me in my work, I also know that I am in danger of putting autism into a medical model. It is true that autistic people struggle with social interaction, but I wonder what would happen if we all stopped seeing autistic people as having a ‘disorder’ or a condition that needed ‘treatment’ and starting seeing people who see the world from a different perspective, and who ultimately have to negotiate a social world that was not designed for them?

Jessie, the young autistic lady who I have had the pleasure to work with and become friends with, once wrote the following words to me after she had been coming to our day service for a couple of years following her late diagnosis: ‘I now live in a world willing to adjust to me’. So, just like she says, I think we should all try to adjust our communication, our behaviour, our perspective, our intervention and our world. Because in doing that, Jessie (and other autistic people) can have more opportunities to experience success in how she lives her life, and how she interacts with others in this social world. How rewarding is that?
Key points from Chapter 11

This chapter covered social skills and the person with autism.

A diagnosis of ASD

There are two essential features of ASD: firstly, the child (or adult) will experience ‘persistent deficits in social communication and social interaction’, and secondly, ‘restricted, repetitive patterns of behaviour, interests or activities’ (DSM-5, 2013). Social skills deficits can be divided into three symptoms:

1. Deficits in social-emotional reciprocity
2. Deficits in nonverbal communicative behaviours used for social interaction
3. Deficits in developing, maintaining and understanding relationships

We looked at six areas of difficulty for the person with ASD:

Social use of language

Most of our communication happens nonverbally (93%) and we have rules that govern our social use of language (often referred to as ‘pragmatics’). Communication also happens within a social context and so it is not just the words that people choose to speak, but all the other messages that are sent which are difficult for the autistic person to pick up on.

Conversational skills

Conversations with an autistic person can include moments where there appears to be a breakdown in communication ‘transmission’. They may stop talking, take over the conversation, interrupt or change the topic and speak in monologues. We see difficulties with all stages: listening, starting, maintaining and ending a conversation.

Literal understanding of language

Understanding figurative speech is often hard, as it requires us to identify subtle relationships between words and phrases, understand the meaning based on our prior experience (or knowledge), and then to take the perspective of the speaker. Figurative messages include metaphors, idioms, sarcasm, puns and similes.
Body language
A deficit in nonverbal communication is a symptom of ASD and a description of ‘clumsy or gauche’ body language is also included in the diagnostic criteria for Asperger Syndrome. We will see difficulties in all aspects of body language, including use of eye contact, facial expression, gesture, distance, touch, posture and fidgeting.

Prosody
When listening to the speech of an autistic person, we can often hear unusual patterns in their paralinguistic skills.

Relationships
Friendships and relationships are complicated, emotional and unpredictable, which makes them all very challenging for the autistic person.

We looked at four theories of ASD and how they affect social communication:

1. Theory of mind. Theory of mind means the ability to recognise and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next. Autistic people have a delayed ToM which leads to difficulties with reciprocal interaction.

2. Weak central coherence. This second theory suggests that autistic people have problems in integrating information to make a coherent, global picture. This means that they may not see the whole social picture and this may lead to inappropriate behaviour.

3. Empathising-systemising. According to the empathising-systemising theory, autism and Asperger syndrome are best explained not just with reference to empathy (below average) but also with reference to a second factor (systemising), which is either average or above average. It is sometimes referred to as the ‘extreme male brain theory’.

4. Executive dysfunction. Some of the core features of autistic people are best explained by an inability to plan actions (executive control) and shift attention, such as transitioning.
### Table 11.5 My top ten tips for working with an autistic child

<table>
<thead>
<tr>
<th>Think about . . .</th>
<th>In particular . . .</th>
</tr>
</thead>
</table>
| 1. The environment| Is there communication overload?  
|                   | Is there sensory overload?   
|                   | Is someone sensitive to a particular sense?  
|                   | Consider seating, colour/patterns, perfume, noise etc. |
| 2. The task       | One task at a time.  
|                   | Think about instructions.  
|                   | Think about routine.  
|                   | Think about the use of visuals or paper and pens. |
| 3. Their anxiety  | New situations will make them anxious.  
|                   | Prepare them in advance.  
|                   | Explain it clearly.  
|                   | Give the person a time and stick to it.  
|                   | Keep a routine as much as possible. |
| 4. Their          | How much do they understand?  
| communication     | What is the best way to help them to express themselves?  
|                   | What are their specific difficulties? |
| 5. Your verbal    | Be clear and specific.  
| communication     | Avoid abstract or ambiguous language.  
|                   | Repeat if necessary but keep same word order.  
|                   | Check that they have understood. |
| 6. Your nonverbal | Use clear body language to back up what you are saying.  
| communication     | Use a calm tone of voice. |
| 7. Feedback       | Encourage feedback.  
|                   | Give feedback on their performance.  
|                   | Get feedback on your performance. |
| 8. Taking things  | Communication can sometimes be blunt.  
| personally        | Try not to take this personally.  
|                   | There is mostly no malice or forethought. |
| 9. Time           | Consider ‘chill-out’ spaces or ‘alone time’.  
|                   | Bring in options for someone to take time away from others. |
| 10. The ‘why’     | If the person behaves in an unexpected or challenging way, always ask why?  
|                   | What are they communicating?  
|                   | How can you help? |
HERE ARE TWO strands to the history of autism – the history according to professionals, mostly clinicians and latterly researchers, and the history according to autistic people and their families. Here we provide a brief overview of key influential figures from both strands, who have helped to shape how autism is viewed today.

1. Kanner’s autism

He wandered about smiling, making stereotyped movements with his fingers, crossing them about in the air. He shook his head from side to side, whispering or humming the same three-note tune. He spun with great pleasure anything he could seize upon to spin. . . . When taken into a room, he completely disregarded the people and instantly went for objects, preferably those that could be spun. . . . He angrily shoved away the hand that was in his way or the foot that stepped on one of his blocks.

(Kanner, 1943; reprinted in Kanner, 1973)

This description of a 5-year-old boy called Donald was written over 70 years ago in Kanner’s landmark paper *Autistic Disturbances of Affective Contact*. The term “autistic” comes from Bleuler (1908), who used the word (from the Greek “autos” meaning self) to describe the social withdrawal seen in adults with schizophrenia. Despite radical changes in our conceptualisations of autism, clinicians and teachers today still remark on similar features to those described by Kanner so many years ago. Moreover, autism has almost certainly always existed. Folktales can be found in nearly every culture that tell stories of individuals with unusual behaviour and a literal interpretation of the world. The following stories come from two very different cultures, but each centre on a character who we might now describe as autistic. The first tale comes from India:

One time Sheikh Chilli was hotly in love with a girl, and he said to his mother: “What is the best way of making a girl fond of one?” Said his mother: “The best plan is to sit by the well, and when she comes to draw
water, just throw a pebble at her and smile”. The Sheikh went to the well, and when the girl appeared, he flung a big stone at her and broke her head. All the people turned out and were going to murder him, but when he explained matters, they agreed that he was the biggest fool in the world.

(From 151 Folktales of India, Kang & Kang, 1988)

The second folktale comes from Malta:

In a village, there lived a boy called Gahan. It was Sunday and Gahan's mother wanted to go to church early. But Gahan didn't like getting up in the mornings, so he said he would stay in bed. When his mother was ready to go, she came into Gahan's room. “I'm off to church now”, she said. “When you get up, if you decide to come to the church, be sure and pull the door behind you”. “Don't worry, mother”, said Gahan, “I won't forget”. After a while Gahan climbed out of bed, washed and dressed and was just about to leave when he remembered what his mother had said. He opened the front door, pulled it down, held it by the knocker and began to pull it along behind him. You can imagine how all the people laughed when they saw Gahan walking along the street dragging the door behind him. When he arrived at the church he walked straight in. But he made such a banging and clattering noise that everyone turned to see what was happening. They, too, thought that it was very funny, but Gahan's poor mother was very embarrassed. “What on earth are you doing?” she asked. “Well, mother”, answered Gahan, “you asked me to pull the door behind me if I left the house, didn't you?”

(From Folktales from Australia's Children of the World, Smith, 1979)

These tales suggest that the unexpected behaviours of people with autism have been recognised in many different cultures over the centuries. But it was not until Kanner wrote about a group of 11 children with a puzzling but similar constellation of features that autism was clinically recognised. These features, as described by Kanner, included the following:

*Extreme autistic aloneness*: the children did not relate to people as expected and appeared to be happiest when left alone.

*Anxiously obsessive desire for the preservation of sameness*: the children were extremely upset by changes of routine or surroundings, such as a different route to school, or a rearrangement of furniture.

*Excellent rote memory*: the children Kanner saw showed an ability to memorise large amounts of material (e.g. an encyclopaedia index page), which was out of line with their apparent learning difficulties.

*Delayed echolalia*: the children repeated language they heard, but did not appear to use words to communicate beyond their immediate
needs. They would also use “you” when referring to themselves and “I” for the other person (termed “pronoun reversal”), following from a direct repetition of the other speaker’s remark. In the same way, children with autism may use the whole of a question instead of a typical request (e.g. “Do you want a sweet?” meaning “I want a sweet”).

Hyper-sensitivity to stimuli: Kanner noticed that many of the children he saw reacted strongly to certain noises and to objects, such as vacuum cleaners, elevators and even the wind. Some also had feeding problems or would eat only a very restricted diet.

Limitation in the variety of spontaneous activity: shown in the children’s repetitive movements, verbalisations and interests. However, Kanner felt that the children showed a good relation to objects, such as dexterity in spinning things or completing jigsaw puzzles.

Good cognitive potentialities: Kanner believed that the outstanding memory and dexterity shown by some of his cases reflected a superior intelligence, despite the fact that many of the children had been considered to have severe learning difficulties.

Highly intelligent families: Kanner remarked that all his cases had intellectual parents. However, this is probably due simply to a referral bias – Kanner’s sample is unlikely to have been representative; only the well-connected managed to see the famous child psychiatrist at Johns Hopkins Hospital.

In his later writing (Kanner & Eisenberg, 1957), Kanner isolated just two of these many features as the key elements of autism: “Extreme isolation and the obsessive insistence on the preservation of sameness”. The other aspects he considered to be either secondary to and caused by these two elements (e.g. communicative impairments), or nonspecific to autism (e.g. stereotypies). In Chapter 3, we will reassess Kanner’s description of autism and consider changing diagnostic criteria in relation to that original set of case studies.

2. Asperger’s autism

While Kanner is often considered the first person to have characterised autism, Hans Asperger was working at the same time in Austria with a group of children he also identified as having a shared set of features (Asperger, 1944). Recent examinations of the history of autism research and clinical practice have raised the question of whether Asperger ‘got there first’ and Kanner partly drew on his original work (Silberman, 2016). This possibility may have been hidden by the fact that it took many decades for Asperger’s work to be translated from the original German (Asperger, trans. Frith, 1991). Questions have also been raised, just as we were finalising this book, about Asperger’s work under the prevailing Nazi regime, with a new paper revealing a disturbing level of
complicity from the physician (Czech, 2018). Asperger’s writings have shaped our understanding of the condition and cannot be ignored in the history of autism. As we write, the autism community is adjusting to the shocking new information about Asperger’s role in the evil treatment of disabled children by the Nazi death machine and discussing whether the term ‘Asperger’s syndrome’ (no longer in the diagnostic manuals) is still appropriate and acceptable.

Kanner and Asperger were both foundational to our understanding of autism and their descriptions are similar in many ways. Both men believed the social differences in autism to be innate (in Kanner’s words) or constitutional (as Asperger put it) and to persist through life into adulthood. In addition, Kanner and Asperger both noted the children’s lack of eye contact, their stereotypes of word and movement, and their marked resistance to change. The two authors report the common finding of isolated special interests, often in idiosyncratic objects or topics. Both seem to have been struck by the attractive appearance of the children they saw. Kanner and Asperger make a point of distinguishing the disorder they describe from schizophrenia, on the basis of three features; the improvement rather than deterioration in their patients, the absence of hallucinations and the fact that these children presented as autistic from their earliest years. Lastly, both Kanner and Asperger believed that they had observed similar traits – of social withdrawal or atypicality, intense delight in routine and the pursuit of special interests to the exclusion of all else – in the parents of many of their patients.

There are three main areas in which Asperger’s and Kanner’s reports disagree, if we believe that they were describing the same sort of child. The first and most striking of these is the child’s language abilities. Kanner reported that 3 of his 11 patients never spoke at all and that the other children did not use what language they had to communicate. Asperger, by contrast, reported that each of his four case study patients (and, by implication, most of the unspecified number of such children he met) spoke fluently – even “like little adults”. Asperger notes their “freedom” and “originality” in language use, and reports that two of his four cases had a tendency to tell “fantastic stories”.

Asperger’s description also conflicts with Kanner’s on the subject of motor abilities and coordination. Kanner (1943) reported that “several of the children were somewhat clumsy in gait and gross motor performance, but all were very skillful in terms of finer muscle coordination”. Asperger, by contrast, described all four of his patients as clumsy and recounted their problems not only with school sports (gross coordination) but also with fine motor skills such as writing.

The last area of disagreement in the clinical pictures painted by Asperger and Kanner is that of the child’s learning abilities. Kanner believed that his patients were best at learning rote fashion, but Asperger felt that his patients performed “best when the child can produce spontaneously” and suggests that they are “abstract thinkers”. The same dichotomy can be observed in different approaches to autistic support and education today.
How are we to understand and resolve these contradictions? One possibility is to separate what we refer to as autism into sub-categories: autism vs. Asperger’s syndrome. Indeed, these sub-types were introduced into previous iterations of the diagnostic manuals (more on this in Chapter 3). Another is to consider autism in terms of a spectrum that varies not only between people but also across the lifespan and in different contexts. This was the main contribution made by our next foundational clinician-researcher in the history of autism, Lorna Wing.

3. Wing’s autism

For a long time, autism research moved slowly – although researchers such as Michael Rutter and Eric Schopler were publishing new ideas and results, attention to this ‘very rare’ condition was limited and major developments did not take place until some decades later. At that point, Lorna Wing – an exceptional clinician, researcher and the parent of an autistic daughter – began to pioneer a new understanding. Next, we provide a few more examples of how parents of children with autism have shaped understanding, awareness and especially service provision. However, a more in-depth history of autism research and practice can be found elsewhere (Feinstein, 2011; Donvan & Zucker, 2017), revealing the massive contribution made by people – such as Bernard Rimland in the USA – who had both family and professional knowledge of autism.

In 1979, Wing and her colleague Judith Gould published a seminal paper, which first introduced what came to be called the “triad of impairments” (Wing & Gould, 1979). The paper reported on a large epidemiological survey, raising the methodological bar relative to the groups of case studies which had been used to define autism up to that point. Drawing on a screened sample of 914 children, and detailed data from 132, Wing and Gould grouped the features of autism into three categories: social interaction, communication and imagination. Social interaction and communication difficulties aligned closely with the original observations by Kanner (and Asperger, though at that time, his work was not yet known in England). Wing and Gould noted atypicalities in the interaction styles of children and absence, or unusual use, of speech. The ‘imagination’ domain was a novel way to conceptualise the presence of repetitive and stereotyped behaviours, as well as unusual styles of play, especially an absence of pretending, or “symbolic play”. Later, this work was re-capitulated in adults (Shah et al., 1982), detecting the same clusters of features in a large clinical sample. This last observation, of reduced pretend play, was also foundational to the ‘Theory of Mind’ (ToM) account of autism (see Chapter 5).

Wing and Gould’s paper also introduced a new way to sub-categorise children based on their social approach style (at any one point in time) into one of three groups (see Figure 2.1 and also Castelloe & Dawson, 1993):
Aloof: these children were described as being either “aloof and indifferent in all situations” or as making social contact in order to satisfy a need, but then retreating immediately.

Passive: this group accepted social contact, but did not seek it out. In the playground, for example, they might be given a role in a play scenario, but require direction from their non-autistic peers to sustain it.

Active but odd: these children did approach others to engage in social interaction, but did so in an atypical way. A consequence of their peculiar behaviour was that they “were sometimes rejected by their peers” – an early flag for the fact, now increasingly recognised, that the responses of non-autistic people play a key role in the experience and adaptation of autistic children (Grossman, 2015).

Attempts at sub-grouping have continued using more data-driven approaches (e.g. Grzadzinski et al., 2013; Prior et al., 1998; Stevens et al., 2000) though to date, none of these has proven definitive. Meanwhile, Wing took a different tack with the publication of her book The Autistic Spectrum (1996), which gave prominence to this term, highlighting variability between individuals who share the same broad diagnosis. In particular, Wing emphasised that difficulties and strengths present themselves differently across the lifespan, and in different environmental contexts. Her work, published over a period in which diagnoses of autism were dramatically on the increase, had a particular impact on educational practice as teachers, more than clinicians, began to take responsibility for the progress of children on the autism spectrum.

**FIGURE 2.1** An illustration of Lorna Wing’s “aloof, passive, odd” sub-types

Reproduced from Uta Frith, 1989, with kind permission of the author and of the artist, Axel Scheffler.
4. Myths and controversies

So far, we have emphasised the contributions made by some of the early pioneers to the clinical characterisation of autism. This history of course includes many other key figures, and there is further reading by and about some of these at the end of the chapter. However, the clinical and academic history of autism is also sadly laden with tragic examples of negative characterisations of autism, leading to misguided and sometimes abusive treatments. While we do not have space to explore these in detail, it would be remiss of us to ignore them.

One of the most pervasively damaging theoretical accounts was the so-called refrigerator mother model, a psychogenic theory that attributed the presence of autism in children to a lack of caring and responsive parenting, rather than to a biological cause (see Donvan & Zucker, 2017 for a full history). Blame was laid wholly at the feet of the mother, in line with the heavily gendered parenting roles of the time. Many autistic children were taken from their families and raised in institutions, and mothers were given psychotherapy to try to correct their parenting. One early approach to educating autistic children was Applied Behaviour Analysis (ABA), developed by Ivar Lovaas using the principles of conditioning first established in animals. Children were taught basic skills in discrete steps, using both reward and punishment to encourage ‘correct’ behaviour. While ABA has evolved considerably from this time, and now covers a wide array of approaches, it remains controversial to many for its apparent pursuit of a highly normative ‘ideal’ child, focusing on behaviour alone and reliance on evidence of efficacy that has been considered weak (Dawson et al., 2008).

The often-upsetting history of autism research and practice is essential reading for anyone choosing to specialise in the field. While we designate it as ‘history’, many autistic adults today were raised in this context, and psychogenic theories still have a harmful influence in some parts of the world. For further reading we point our readers to Neurotribes (Silberman, 2016) and In a Different Key (Donvan & Zucker, 2017).

5. Baron’s autism

Thankfully, many parents survived the damage done by psychogenic theories and have been prominent in shaping research, and especially practice. Michael Baron, whose son was one of the earliest children diagnosed with autism in the UK, founded a school for autistic learners, together with other parents. This group went on to evolve into today’s National Autistic Society (NAS) which provides information and support to autistic people and their families across the UK. Founded in 1962, the NAS was the first autism association in the world and inspired and fostered similar parent-led groups internationally. In 2003, the National Autistic Society appointed Dr Larry Arnold as their first autistic
trustee – a landmark moment in the autistic rights movement. Scottish Autism was similarly founded by parents, with five families mortgaging their houses to set up what was then The Scottish Society for Autism in 1968 and creating the first autism-specific school in Scotland. Baron continues to be a prominent spokesperson on behalf of autistic people, especially those with a learning disability, and their families.

Parents have also been prominent in shaping public perceptions of autism and have inspired researchers. Browsing in a second-hand bookshop as a student, Francesca chanced upon Clara Claibourne Park’s account (1968) of raising her autistic daughter, which sparked her enduring interest in autism. Almost two decades later, Sue was captivated as a PhD student by Charlotte Moore’s frank and affectionate book (2004) about her autistic sons. Parents have also founded some excellent online resources for learning more about autism, building communities of expertise and shared support – the Thinking Person’s Guide to Autism is an excellent place to start.

The pioneering efforts of parents have left a legacy of charitable autism support organisations and schools from which the community continues to benefit. However, there are also tensions between parts of the autism community (largely driven by non-autistic parents of autistic children) that emphasise a need for cure or rehabilitation versus parts of the community (largely driven by autistic adults) that are focused on acceptance and rights. When the co-founders of Autism Speaks (a USA parent-led charity) visited the UK and spoke about their mission ‘to fight and cure autism’ (making an analogy with fighting cancer), the Something About Us campaign, led by Dinah Murray, was developed to ”establish a creative autistic presence; give autistic people a chance to say what people most need to hear about autism; have the widest possible exposure; rebalance a specific event to diminish Autism Speaks’ impact; create alliances and generate obligations” (Murray, personal communication). Similarly, the title of the book Loud Hands: Autistic People Speaking was selected specifically to counter the notion of “quiet hands” – i.e. no ‘stimming’ or flapping – which is a part of many early intervention programmes. For psychologists working in practice or research, these tensions between different perspectives within the broad community of stakeholders can be challenging to navigate and interpret. Being informed about the differing perspectives, and the personal experiences which underlie them, is crucial for anyone in the field.

6. Sinclair’s autism

A history of autism cannot be complete without considering the accounts of autistic people. Women have been particularly prominent in this literature – Temple Grandin’s Emergence: Labelled Autistic was the first autistic autobiography and, along with Donna Williams’ Nobody, Nowhere, became a classic in the growing canon of first-person accounts of autism.
There are also academic writers on the subject, one of the most prominent of whom is Jim Sinclair. Sinclair was an early leader for the autistic community, co-founding *Autism Network International* in 1992. Xe\(^1\) has subsequently shaped scholarly argument in support of neurodiversity, writing in 1993 that:

*autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person – and if it were possible, the person you’d have left would not be the same person you started with.*

(Sinclair, 1993)

Later, in *Being Autistic Together* Sinclair describes how *Autism Network International* was set-up and the founders discovered that “the time autistic people got to spend together was precious to many of us. People enjoyed it and wanted more of it” (Sinclair, 2010). As a consequence, the first autistic-led event for autistic people and their allies, *Autreat*, was launched in 1996, inspiring similar events around the world.

Simultaneously in Europe, Martijn Dekker launched *Independent Living on the Autism Spectrum*, or InLv, an online network with the slogan “where those who are different, find that they’re not alone”. Autistic-led organisations are now proliferating and include the *Autistic Self-Advocacy Network* (founded 2006), *Autism Rights Group Highland* (founded 2005) and the *Autism Women’s Network* (founded 2009). In 2005, *Aspies for Freedom* celebrated the first Autistic Pride Day, now celebrated internationally on June 18 every year. More recently, the journal *Autonomy* was launched by autistic academics to publish disability rights and sociological autism research, often by neurodivergent scholars (Arnold, 2013).

Led by autistic advocates, community leaders and scholars, we now find ourselves at a turning point in the conceptualisation of autism. Autistic people have become pioneers of the larger disability rights agenda, emphasising a social model of disability (Shapiro, 1994; Solomon, 2008) and demanding a role in shaping the policies and services that affect their lives (Ne’eman, 2010). This characterises the disabling consequences of autism, like all disabilities, as being the result of an environment that fails to enable individuals who do not operate in the same way as the mainstream majority. A more nuanced account, the post-social model, shifts the focus subtly from the environment as the culprit to the interaction between the individual and their environment (see Chapter 9 for more on this). To take a simple example, someone who doesn’t walk requires both a personal aid (e.g. a wheelchair) and an enabling environment (e.g. ramps, wide doorways) to get around. Disability rights campaigners

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\(^1\) We believe this is Dr Sinclair’s preferred pronoun.
are beginning to have success in placing ableism (prejudice against disabled people) alongside racism, sexism and homophobia as a major source of disadvantage in our society.

7. Neurodiversity

Within the disability rights movement, autism is often characterised as a ‘hidden disability’ – meaning that it is not marked out by obvious physical features. Other hidden disabilities include many of what psychologists term “neurodevelopmental disorders” – e.g. attention deficit hyperactivity disorder, dyslexia, dyspraxia, epilepsy and Tourette's syndrome. Moving away from the negative terminology of ‘disorder’, the term neurodiversity was coined by InLv member Judy Singer, who wrote, “We are beginning to divide ourselves . . . according to something new: differences in ‘kinds of minds’ . . . swinging the ‘Nature-Nurture’ pendulum back towards ‘Nature’” (Singer, 1998). Neurodiversity thus describes variability in brain structure and function, and resulting cognitive processes, accounting for differences between all individuals and, in cases of neurodivergence, also giving rise to diagnostic categories. Neurodivergent people may find that their experiences of the world and of other people do not align with the norm, and this is attributed to basic, underlying neurological differences. Crucially, neurodiversity dictates that neurodivergent people are different, not less.

It is important to emphasise that adopting a neurodiversity stance does not preclude providing support to people in need, nor does it deny the very real challenges experienced by many autistic people and their families. Autism is often accompanied by mental health difficulties (e.g. anxiety, depression), medical conditions (e.g. epilepsy) and behavioural features (e.g. self-harm, poor sleep, limited diet) which have significant negative impact on the individual and those around them. Autism is also associated with intellectual disability in many cases (though see Dawson et al., 2007, for thoughts about intelligence testing and autism). Limited verbal communication and/or additional language impairment presents a significant barrier for many. Even where autism is accompanied by high IQ and fluent speech, it might be categorised as a learning difficulty as it offers barriers to learning, where learning is expected to occur in a typical classroom. All of these issues are worthy of research attention and targeted support. The essence of neurodiversity tells us that, in identifying such areas for support and measuring suitable outcomes, our goal should be to provide relief in areas of need but not to eliminate an individual’s neurodivergent status.

The motto “nothing about us without us” foregrounds the need for disabled people to be involved in all aspects of decision-making about disability. In the context of autism practice and research, we must work closely with autistic people and their allies to deliver research that matters to them (Milton, 2014). This does not mean abandoning psychological theory nor scientific rigour. It does mean developing participatory research practices.
Chapter 2 The history of autism

(Fletcher-Watson et al., 2018; Scott-Barrett et al., 2018) and framing our questions, designing our methods and disseminating our findings in a way that is respectful and embracing of autistic differences.

8. Current debates

Summary

The history of autism has moved through phases, largely influenced by English-speaking clinicians drawing on a series of case studies and then bigger data sets. Increasingly, our conceptualisations of autism are being influenced by autistic scholars and the autistic community. The clinical model of autism at each phase since the condition entered the diagnostic books has influenced the focus of research at that time. Today’s neurodiversity framework is just beginning to have an impact on research, and some of the latest findings in this area are covered in Chapter 9. Much has been learnt about autism, but much still remains to be understood. In the next chapters, the current state of knowledge concerning the behavioural, biological and cognitive nature of autism will be reviewed, and some continuing debates and future research questions are discussed.

Big questions

What is next for our understanding of autism? The autism field has moved through many phases, and we can expect dramatic shifts to come. Can we envisage a future in which autism leaves the diagnostic manuals all together and becomes a self-determined personal identity? If so, what will this mean for the provision of evidence-based supports for the difficulties experienced by autistic people?

How can we cater to diversity within the autistic community? At the moment, the majority of autistic people who are playing a role in shaping research and practice are those without intellectual disability. It remains challenging to engage directly with autistic people who are minimally verbal or learning disabled. The viewpoint of parents can be very valuable here, but these may not easily reconcile with the perspectives of autistic people. Certainly, respect for, and acceptance of, autism must encompass the whole community.

Does “neurotypicality” necessarily exist and what does that mean for neurodivergence? Neurodivergence is used to describe everyone who is categorically distinct from a neurotypical standard. All autistic people are neurodivergent, but not all neurodivergent people are autistic – other neurodivergent people might have ADHD or Tourette’s syndrome, for example. Meanwhile, the term neurodiversity encompasses individual differences between all people. Neurodiversity, like biodiversity or ethnicity, doesn’t automatically imply
that there is a norm from which all others diverge. Instead, we are all different and diverse. Taken this way, how can we use the concept of neurodiversity to encourage greater acceptance, without undermining neurodivergent people's need for support and understanding?

COMMUNITY CONTRIBUTION: MARTIJN DEKKER – AUTISTIC ADVOCATE AND FOUNDER OF AUTISTIC ONLINE COMMUNITY, INLV

The history of autism is one of competing and opposing narratives. As described in this chapter, in the 1940s, Leo Kanner and Hans Asperger described autism in terms of case studies with interpretations: one form of narrative. In the 1960s and 1970s, parents started organising to counter the pernicious narrative that they were responsible for causing their children's autism. Understandably, then, these parents became the centre of their own narrative. Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention came along, offering the promise of normalisation to parents whose autistic children had been written off as hopeless. But if a child failed to be rendered 'indistinguishable from their peers', parents were blamed once again: for not trying hard enough, for not following the method to its painful and harmful extremes, etc. The result was an entrenched attitude of distrust and defensiveness among 'tragic hero' parents.

Meanwhile, autistics were increasingly seen as non-persons. As ABA pioneer Lovaas said in an interview, “You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense” (Chance, 1974). As a result of such attitudes, autistic people were, and in many of the world's places still are, 'disappeared' to institutions, tortured, abused, ignored, etc. Through all the changes and new paradigms, one factor remained constant: the perspective of autistic people was consistently erased from the narrative.

Then, in the early 1990s, the Internet ceased to be a network for the academically privileged and was made available to mere mortals. Autistic people, who previously had no way of communicating with each other, quickly started finding each other online. In 1992, Autism Network International started the ANI-L mailing list, the first online community run for and by autistics. Hosted by Syracuse University, ANI-L quickly started developing its own autistic subculture and political paradigm (Sinclair, 2005).

In 1996, only just diagnosed after a childhood and young adulthood spent being different without knowing why, I entered the scene as the need was felt for an alternative to ANI-L. Long before social media, creating a new online group was difficult, but I already had experience with programming and online communication. Using my home dial-up line and specialist software, I started my own entirely self-hosted set of email groups for and by autistics, emphasising inclusion and diversity instead of one shared culture and one shared set of political beliefs. The group was called InLv, an abbreviation of ‘Independent Living on the autistic spectrum’.
Spread over many parts of the world, participants discovered their autistic identity through a shared, yet deeply personal, exploration of a different way of being. For all our cultural, political and neurological diversity, we found plenty in common, not only in the shared experience of trauma and marginalisation but, for many of us, also in a certain fundamental autistic way of being (Dekker, 1999). Text-only communication proved a gateway to understanding, not a barrier. ‘Autism’ became my key for belonging, for the first time in my life, to a community of some description. The idea of being autistic became embedded in my sense of identity.

Early on, the notion emerged from discussions on InLv that human neurology is innately diverse, an aspect of biodiversity, and that this neurodiversity (Singer, 1998) is as valuable to the human ecosystem as any other form of diversity. We conceived neurodiversity as an inherently inclusive notion. Far from ‘dictating’ that neurodivergent people are ‘different, not less’, we were very much including those of us who felt less or broken, accepting them as human beings on par with those who felt non-disabled or even superior. Neurological diversity does not prescribe anything, such as how one should consider one’s own condition. It simply exists; it’s a fact. What we were advocating was the political recognition of the logical and ethical consequences of that fact – that is, equal rights for all neurodivergent people, including our right to exist, live, love, work, procreate, etc., like anyone else.

These days, neurodiversity activism has, in large part, moved beyond that original idea. Many now promote a specific and prescriptive ‘paradigm’ that, by claiming there is no such thing as a suboptimal neurological configuration (Grace, 2015; Walker, 2014), excludes autistic people who find themselves disabled or broken. Too often, I hear of autistic people joining a group of neurodiversity advocates hoping to meet kindred spirits, only to find themselves being told precisely what to believe, how to identify and how to communicate, with any perceived transgression resulting in a swift ban (e.g. O’Leary, 2018). An ironic situation for a movement founded on the idea of embracing diversity.

Like those 1960s–1970s parents trying to prove they didn’t cause their children’s autism, autistic activists these days are ever more distrustful and defensive. In trying to defend our right to exist, we are falling into the trap of taking our own narrative too seriously. The challenge neurodiversity activists face as we approach the 2020s, then, is basically one of growing up and learning once again to accept those who are different from ourselves.

Section references


Chapter 2  The history of autism

Autism By Sue Fletcher-Watson and Francesca Happé


Recommended reading


