

Chapter 1:

What is autism?

Introduction

You may already know something about autism, but in case you don't, and so that you have as much of the information you need in one book, we look at the core features of autism and how individuals on the spectrum vary one from another. We look at the number of people on the autism spectrum, the causes of autism, and when autism begins. We also consider the different types of autism and how they are categorised and diagnosed. We end with a discussion of what happens to people on the autism spectrum as they get older and whether autism is a disability or a difference.

Core features

Scientists classify autism as a neurodevelopmental disorder, that is, a condition which affects the development of the brain (1). Individuals on the autism spectrum vary enormously from each other but they all share the two 'core' features of autism (2):

- Persistent difficulties with social communication and social interaction. For example, they may find it hard to begin or carry on a conversation, they may not understand social rules such as how far to stand from somebody else, or they may find it difficult to make friends.
- Restricted, repetitive patterns of behaviour, interests, or activities. For example, they may develop an overwhelming interest in something, they may follow inflexible routines or rituals, they may make repetitive body movements, or they may be hypersensitive to certain sounds.

Individuals on the autism spectrum also face many other issues, problems and challenges on a day-to-day basis which are covered in more detail in Chapter 2 (see page 27).

Autism is a spectrum

People on the autism spectrum can be very different from each other, even though they share the core features of autism. For example, some people may have little or no speech, whereas others may be highly articulate, although their speech may be stilted, and they may not have mastered the art of conversation (taking turns during conversations and recognising the conventions of a conversation) (3).

Some people with autism may take language very literally – for example misunderstanding ‘It’s raining cats and dogs’ – while others may understand that this is a metaphor, but still think in very literal terms, for example by assuming that a person will do precisely what they say they will do.

Some people may expect a person to arrive at the exact time they said they would arrive, and become anxious if they don’t. Other people may be more flexible.

Some people with autism have an uneven profile of abilities (see Figure 1.1). This means that they may be very good at certain things (for example, social interaction), but may not be very good at other things (for example, thinking flexibly).

The important thing to remember is that every person with autism is different. This has an impact on the interventions that are used for these people, and whether they will work. We discuss this in Chapter 3 (see page 38).

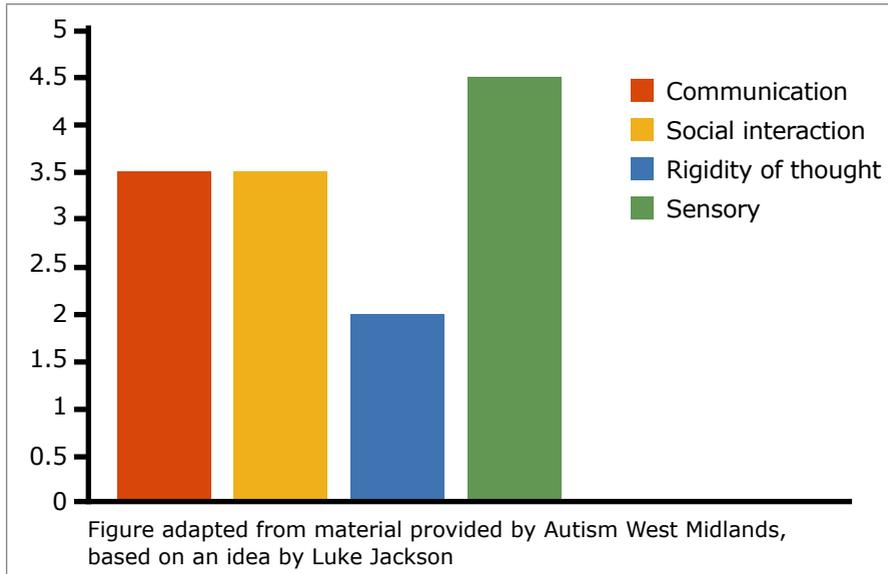
Numbers and statistics

There are approximately 700,000 people in the UK on the autism spectrum – over one per cent of the population. However, some people believe the numbers may be higher than this (4–6).

The number of people on the autism spectrum appears to have risen dramatically over the past two decades, although the reasons for this are unclear. Most of the increase may be explained by increased awareness of autism, changing diagnostic criteria, better diagnosis, and a phenomenon known as ‘diagnostic substitution’ (where the prevalence of one condition increases while another decreases because it is discovered that people were misdiagnosed,

so their diagnosis is changed) (7). There may also be a small increase in the actual number of people on the autism spectrum.

Figure 1.1: Profile of abilities



Autism is believed to affect on average four times as many men as women (8). However, this depends on the level of ability, with only twice as many men affected as women if they have severe learning disabilities and around 10 times as many men affected as women in Asperger syndrome (9). This may partly be due to men being more prone to autism, as seen in some genetic studies (10). But it is also partly due to a current lack of knowledge of how autism shows itself in women (11). Women with autism are often more easily able to hide their difficulties and blend in. However, the efforts they make to do this can be exhausting and can result in mental health problems. Furthermore, much of our knowledge of autism is based on observation and study of boys – diagnostic criteria and assessment tools are all designed based on a male picture of autism, making it all too easy to miss women and girls at diagnosis. Little is known about the prevalence of autism in older age groups. Studies suggest that the prevalence of autism is similar across age

groups which implies that over one per cent of the older population may also have autism (12). However, this group has not received much attention. It is only recently, as the original cases of autism diagnosed in the 1940s, 1950s and 1960s reach old age, that the needs of the ageing autism population are being considered. Much more needs to be done, as many older people are currently undiagnosed and there is very little specific guidance on supporting older people with autism (13).

Causes

Autism has no single cause. Most researchers believe that autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors which may affect a variety of parts of the brain. The Medical Research Council reported:

‘Research over the last half century has established autism as a neurodevelopmental disorder. Early suggestions that ASDs [autism spectrum disorders] might result from abnormal parenting have been abandoned in the face of overwhelming evidence for a biological basis and a strong genetic component. Most researchers believe that ASDs have a variety of causes, perhaps all affecting the same brain systems, or impeding development through disruption of different abilities necessary for social and communicative development. Whether environmental factors interact with genetic susceptibility is as yet unclear.’ (14)

Onset and regression

According to the National Institute for Health and Care Excellence (NICE) autism is present from early childhood, although features may not always be visible until social demands exceed a child’s capabilities. For example, features may become apparent when starting at nursery or school or moving to secondary school. Some parents may notice that their child is different from birth while others may not notice until they are older (15).

Some children (between one fifth and one third of children) appear to develop normally and then regress, losing skills they previously had. According to NICE, this usually occurs in the

second year of life for unknown reasons (15). Regression which occurs after the age of three years is very rare and is termed 'childhood disintegrative disorder'.

Diagnosis

Getting a diagnosis of autism can be a positive thing as it can provide an explanation for some of the difficulties a person may be experiencing, as well as allowing access to services and support. The process of getting a diagnosis varies from country to country and sometimes even within the same country.

In the UK, the first step of the process is to contact a GP, health visitor or special educational needs co-ordinator (SENCO) who will then refer you to specialist diagnostic services. However this is not always a straightforward process as some professionals may be reluctant to start the process, and there may be a lack of specialist diagnostic services in some areas, especially for adults (16).

Diagnostic tools

The diagnostic assessment can take some time. It is based on developmental history and the use of various tools to assess areas of difficulty. A number of 'gold standard' tools such as the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R) are used, but no tool will be used by everyone, so your diagnosis session may be different.

In adults, diagnosis can be more challenging as there are fewer diagnostic tools that are appropriate for adults. Furthermore, it can be harder to obtain a developmental history because the person with autism may not have anyone who can give details of their early childhood (16).

Diagnostic manuals

Two major diagnostic manuals are used to diagnose autism, and both are reviewed and updated on a regular basis:

- The Diagnostic and Statistical Manual of Mental Disorders (DSM) is mainly used in the USA and the latest version, DSM-5, was updated in May 2013.
- The International Classification of Diseases (ICD) is mainly used in Europe and the latest version, ICD-10, is due to be updated in 2017 (17).

The recent update of the DSM means that the diagnostic criteria for autism in the two manuals are currently different. The ICD-10 uses three areas of difficulty to define autism (the triad of impairments): difficulties in social interaction, difficulties in social communication and repetitive and restrictive behaviours (18). The DSM-5, on the other hand, uses two broad categories – difficulties in social communication and social interaction, and repetitive and restrictive behaviours and sensory issues (2).

We use the DSM-5 criteria in this book since we believe that when the ICD is revised it will probably also switch to two, rather than three, core features of autism.

Specific diagnoses

The current version of the Diagnostic and Statistical Manual of Mental Disorders, DSM-5, uses the 'umbrella term' of 'autism spectrum disorder' (ASD) to describe any form of autism. The previous version, DSM-IV, broke down autism into various sub-groups including autistic disorder, Asperger syndrome, and pervasive developmental disorders not otherwise specified (19). This is also still the case in the ICD-10.

- Autistic disorder (also known as autism, classic autism or Kanner's autism) – describes individuals who have the core features of autism including a clinically significant delay in language.
- Asperger syndrome (also known as Asperger's disorder) – describes individuals with no clinically significant delay in language but who still have the core features of autism. People with Asperger syndrome are often highly intelligent.

- Pervasive developmental disorders not otherwise specified (also known as PDD-NOS) – describes individuals who do not fit into the diagnosis of either autistic disorder or Asperger syndrome but who do have clear features of autism which warrant a diagnosis (18).

The recent change to the Diagnostic and Statistical Manual of Mental Disorders has caused some controversy and some people are worried that the new diagnostic criteria will mean that some individuals with Asperger syndrome or PDD-NOS will no longer qualify for a diagnosis of autism and therefore not receive the services to which they are entitled (20).

Please note: we use the term 'people on the autism spectrum' to refer to anyone with a diagnosis or suspected diagnosis of any kind of autism.

Levels of ability

Some people describe individuals on the autism spectrum as either 'high-functioning' or 'low-functioning' (sometimes known as 'severe' autism).

People with high-functioning autism have a non-verbal IQ of 70 or more, while people with low-functioning autism have a non-verbal IQ lower than 70 (and may also be non-verbal or have very limited speech).

High-functioning autism and Asperger syndrome may be the same thing (this is still being debated). Most research has not shown enough difference to justify it being a separate diagnosis. However, some researchers do believe high-functioning autism and Asperger syndrome are different and need to be separated at diagnosis.

The terms 'high-functioning' and 'low-functioning' autism are also debated. Some people say they are not useful or they are insulting. For example, some individuals classified as having 'severe' autism may be highly intelligent and can function very well with the right kind of support. Some 'high-functioning' individuals on the autism spectrum, on the other hand, may face considerable difficulties which are overlooked because they appear to be coping (21, 22).

Outcomes

When describing autism, the focus tends to be on a person's difficulties. However, people with autism often have significant strengths such as a good eye for detail, an excellent memory for facts and figures and a high level of accuracy and reliability. Some also have considerable creative talent.

People with autism often have significant problems and other conditions such as mental health problems, epilepsy, sensory issues and gastrointestinal problems. These can lead to difficulties at school, in the workplace or making friends. However, with the right support tailored to individual needs, some people with autism can lead relatively independent lives. Others will continue to need support and understanding throughout their lives (15, 23).

Neurodiversity

Some people on the autism spectrum claim that autism is not a disorder but simply an expression of neurodiversity. In other words, autism is a difference, not a disorder (24).

'People need to get over the idea that the neuro-typical way is 'right' and any other way is 'wrong'. The AS way is just as valid – in fact better in some respects. We should be accepted in our own right and the emphasis should be on educating NTs [neurotypicals] not to be so discriminatory and to get over the absurd and offensive idea that they are better than anyone else. People with AS don't need to be 'cured' or trained as to how to 'pretend' to be normal – it is the 'normal' people who need to learn that, contrary to what they think, they are not the pinnacle of God's creation and that there is in fact a lot they could learn from Aspies. They need to be taught not to be prejudiced and discriminatory and to accept and accommodate us for who we are.' (25)

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