

Understanding autism



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Overview and guidance

The autism spectrum

Understanding autism is a free badged course which lasts 8 weeks, with approximately 3 hours' study time each week. You can work through the course at your own pace, so if you have more time one week there is no problem with pushing on to complete another week's study.

Across the 8 weeks of *Understanding autism*, you will engage with key topics including how autism affects children, adults and families, how the condition was first identified and how ideas and understanding have evolved in the decades since. You will consider current ideas about what causes autism, the challenges faced by autistic individuals and their families, and what forms of help and support are available. You will learn that no two cases of autism are completely alike, giving rise to the concept of an autism spectrum.

The course includes authoritative overviews of what is known, and equally important, highlights the significant gaps in our knowledge. The material includes the work of autism professionals – researchers and clinicians for instance, and also the 'inside' perspectives of autistic individuals and family members: all these viewpoints play a role in understanding autism.

Knowledge about autism and provision of services and support have tended to advance more rapidly in countries such as the UK and the US where resources are more plentiful. The course therefore draws extensively on the insights and provision developed in such settings. But autism is a global concern, and it is equally important to consider how cultural differences may affect awareness and understanding of autism, and the particular challenges it poses in low income countries where resources are scarce.

Tell us a little about yourself

Before reading further, please take a few minutes to tell us about yourself and why you are studying the course via this [survey](#).

Terminology in the autism field

Throughout the course, you will engage with a range of different ideas about what autism means to autistic individuals and their families, and how it should be approached by society. This includes a range of views on the most appropriate language for this field. Some key points are noted here:

Autism or autism spectrum?

In this course the terms 'autism' and 'autism spectrum' will be used more or less interchangeably.

'Person with autism' or 'autistic person'?

Some years ago, the National Autistic Society of the UK recommended ‘person with autism’ arguing that ‘autistic person’ and similar phrases were demeaning to the individual. Yet, as it turns out, many adults on the spectrum prefer the latter phrase. This course predominantly adopts the second usage, but recognises the range of views on these language choices

Autism Spectrum Disorder or Autism Spectrum Condition?

Though the formal diagnostic criteria use the phrase ‘Autism Spectrum Disorder’ (ASD), many people reject the medical and disability implications of this phrase. The more neutral phrase ‘Autism Spectrum Condition’ or ASC will be used in this course. We recognise that for some even the term ‘condition’ may seem an unacceptable label for a way of engaging with the world which is just an aspect of human diversity. You will encounter some different views on this during the course.

Difficulty, disability or difference?

Autism involves characteristic traits – ways of behaving and interacting with the world – which differ from those of others in the population. Many of these differences are undoubtedly challenging for the individual and their family, and ‘difficulty’ is therefore a reasonable term to use. Some of these difficulties may also be disabling. But seeing autism characteristics purely as ‘difficulties’ or ‘disabilities’ is an oversimplification. What other people perceive as ‘difficult behaviour’ may be unproblematic or fulfilling for the person with autism themselves. What is disabling for one autistic individual may not be experienced as such by another. Differences may also take the form of very positive traits. Where possible, then, the term ‘difference’ will be employed in this course, rather than difficulty or disability. But it is nonetheless important to acknowledge the serious challenges that certain differences present for people with autism.

As you can begin to see, the issues underlying different uses of language in the autism field are controversial, and have no easy or universally accepted answers. You will encounter these issues again at points during the course, and we will also give you suggestions for further reading.

Acronyms

Acronyms are small groups of letters used to stand for longer phrases or descriptions e.g. U.K. stands for United Kingdom. You will encounter quite a lot of acronyms in the autism field e.g. NAS for National Autistic Society. All are fully introduced, usually with an accompanying glossary entry. Try to familiarise yourself with these acronyms, some of which are tested in quiz questions.

Special study features:

- Each week opens with five specific Learning Outcomes and a brief video overview of the week’s work from course author, Dr Ilona Roth.
- Regular text activities encourage your active engagement with video clips and other materials. You can record your answers in the text boxes provided and refer back to them at any time.
- The interactive glossary will help you with new and unfamiliar terms. If you click on any term that is in bold in the text, a definition or explanation will pop up. You can also search through the whole glossary, which you will find [here](#).
- An interactive quiz at the end of each week is designed for you to test your learning. Passing the quizzes for weeks 4 and 8 will enable you to gain a badge for the course – see the next page of this introduction for further information.

- Key articles and resources cited in the text are listed as references at the end of the week. A list of further recommended reading and other resources is provided at the end of the course.

Learning outcomes for the course:

After completing this course, you will be able to:

- outline what is meant by autism, why it is considered a spectrum, and how it affects different individuals and families
- appreciate different approaches to understanding autism, including theoretical and clinical perspectives and personal accounts
- outline key features of psychological, neurobiological and genetic explanations of autism
- explain key aspects of diagnosis, intervention, education and life-span development
- understand topical issues including neurodiversity perspectives, autism prevalence in women and autism in global context.

Moving around the course

In the ‘Summary’ at the end of each week, you can find a link to the next week. If at any time you want to return to the start of the course, click on the ‘Course content’ link displayed in the sidebar on any page. This page lists all weeks of the course, showing how much of each week you have completed. Click on the arrows beside each week to display a more detailed breakdown of your progress through that week – green ticks indicating the pages you have already visited. You can use this to navigate to any part of the course.

Alternatively, you can use the numbered week links at the top of every page of the course. It's also good practice, if you access a link from within a course page (including links to the quizzes), to open it in a new window or tab. That way you can easily return to where you've come from without having to use the back button on your browser.

What is a badged course?

While studying *Understanding autism* you have the option to work towards gaining a digital badge.

Badged courses are a key part of The Open University’s mission *to promote the educational well-being of the community*. The courses also provide another way of helping you to progress from informal to formal learning.

To complete a course you need to be able to find about 24 hours of study time, over a period of about 8 weeks. However, it is possible to study them at any time, and at a pace to suit you.

Badged courses are all available on The Open University’s [OpenLearn](#) website and do not cost anything to study. They differ from Open University courses because you do not receive support from a tutor. But you do get useful feedback from the interactive quizzes.

What is a badge?

Digital badges are a new way of demonstrating online that you have gained a skill. Schools, colleges and universities are working with employers and other organisations to develop open badges that help learners gain recognition for their skills, and support employers to identify the right candidate for a job.

Badges demonstrate your work and achievement on the course. You can share your achievement with friends, family and employers, and on social media. Badges are a great motivation, helping you to reach the end of the course. Gaining a badge often boosts confidence in the skills and abilities that underpin successful study. So, completing this course should encourage you to think about taking other courses.



How to get a badge

Getting a badge is straightforward! Here's what you have to do:

- read each week of the course
- score 50% or more in the two badge quizzes in Week 4 and Week 8.

For all the quizzes, you can have three attempts at most of the questions (for true or false type questions you usually only get one attempt). If you get the answer right first time you will get more marks than for a correct answer the second or third time. Therefore, please be aware that for the two badge quizzes it is possible to get all the questions right but not score 50% and be eligible for the badge on that attempt. If one of your answers is incorrect you will often receive helpful feedback and suggestions about how to work out the correct answer.

For the badge quizzes, if you're not successful in getting 50% the first time, after 24 hours you can attempt the whole quiz, and come back as many times as you like.

Please note that quiz questions using drag and drop do not work on a mobile device. Instead, you should use a tablet or desktop.

We hope that as many people as possible will gain an Open University badge – so you should see getting a badge as an opportunity to reflect on what you have learned rather than as a test.

If you need more guidance on getting a badge and what you can do with it, take a look at the [OpenLearn FAQs](#). When you gain your badge you will receive an email to notify you and you will be able to view and manage all your badges in [My OpenLearn](#) within 24 hours of completing the criteria to gain a badge.

Get started with Week 1: Introducing the autism spectrum.

Week 1: Introducing the autism spectrum

Introduction

By the end of this week you should be able to:

- evaluate and update your own knowledge of autism
- express a general overview of autism and why it is considered a spectrum
- understand different ways of gaining evidence and insights into autism
- appreciate some different experiences of autism
- understand key milestones in autism history.

Now watch the video in which Dr Ilona Roth introduces this week's work.

Video content is not available in this format.

1 Your understanding of autism

In the following activities you will evaluate your own knowledge of autism.

Activity 1 What do you know about autism?

Allow about 10 minutes

To start with, spend about 10 minutes writing some quick notes summarising your current knowledge and understanding of autism. Maybe you already know quite a bit, or maybe you know very little at all, but you will almost certainly come to this course with some ideas.

Provide your answer...

Activity 2 How accurate is your current knowledge?

Allow about 10 minutes

Now take the interactive quiz at this link:

['How much do you know about autism?'](#)

As you work through it, compare your own first ideas about autism with the questions and feedback. Some of the statements are known to be true or false, while for others the answer is uncertain even to the experts. Some information in the quiz is adapted from Roth et al., 2010.

Activity 3 Updating your knowledge

Allow about 15 minutes

Now revise your notes from Activity 1 in light of the quiz feedback. Keep your updated notes to hand as you read the next section.

2 What is autism?

This section gives an overview of key facts about autism. Read it through, and add to your notes again where necessary.

Autism is considered to be a lifelong, **developmental** condition that affects how a person thinks, communicates with and relates to other people, and interacts with the world around them.

Autism is much more common than was previously thought. About one per cent (or one in a hundred) of people in the UK are thought to be on the autism spectrum. You may know someone with autism, or be on the autism spectrum yourself.

The exact causes are still unknown, but there is good evidence that subtly atypical brain function may lie behind the differences in thinking and behaviour. It is also clear that autism is highly **genetic**. Scientific evidence suggests that multiple genes are involved, and different combinations of genes in different families or individuals.

2.1 Main characteristics

The current framework for diagnosing autism identifies two main groups of characteristics. The first concerns **social communication and interaction**: autistic people find it hard to interact socially with others or to make friends. They have communication difficulties – some can't speak at all; others develop speech later than usual; others can speak perfectly well, but have problems with the social aspects of communication. For example, they don't understand when a listener is getting bored by their stories; they may take language very literally or find it hard to get the point of a joke.

The second group of characteristics is 'non-social': autistic people tend to have narrow or unusual interests, such as acquiring lots of information about just one type of dinosaur. They often repeat the same activity, ranging from constantly rocking backwards and forwards or flicking the fingers, to always eating the same foods, or repeatedly watching the same video. These traits are collectively known as **Restricted and Repetitive Behaviours and Interests (RRBIs)**. Finally, most autistic people also have **unusual sensory responses**, such as being overly sensitive to particular sounds, sights or smells, or quite the opposite, for instance being insensitive to sensory inputs such as pain.

While diagnosis is based on these social and non-social difficulties, many autistic people also have enhanced skills such as good attention to and memory for detail, or natural ability with numbers or IT. A very small proportion of individuals on the spectrum have outstanding talents in fields including art and music.

While social, language and sensory challenges may mean that an autistic person finds it hard to function in a mainstream school or workplace environment, with the right support they can flourish. Employers are beginning to realise the benefit to the workplace of attributes often associated with autism, such as mathematical and IT skills, persistence and attention to detail.

2.2 The autism spectrum

Because of the striking differences among individuals with autism, researchers and practitioners usually talk of the '**autism spectrum**'. This emphasises that autistic

individuals may have very different profiles of strengths and weaknesses. **Autism Spectrum Disorder (ASD)** is the term used within formal autism diagnosis. ASD is also used by some researchers and practitioners; however, many prefer the more neutral term **Autism Spectrum Condition (ASC)**.

A proportion of people on the spectrum (up to about 50%) have profound social and communication difficulties often including little or no speech, markedly restricted and repetitive behaviour and interests, and intellectual disabilities. This variant of autism has sometimes been known as classic or **Kanner's autism**, after Kanner, who described autism in 1944 (there will be more on Kanner in Section 6).

Another major group are those who have no obvious language problems and are intellectually capable or even exceptionally bright, while remaining inflexible, bound by routines, struggling to interact socially and communicate effectively. This variant has until recently been diagnosed as **Asperger syndrome** (after the other main autism pioneer). However, sub-types such as Asperger syndrome are being phased out in contemporary approaches to diagnosis. One contemporary approach treats the spectrum essentially as a **continuum** on which all autistic individuals have their own specific profile of strengths and challenges. Another approach maintains the notion of a spectrum, but allocates autistic profiles of strengths and difficulties into some newly defined sub-types. You will read more about this in Week 3.

Autism spectrum conditions can occur alongside other psychological and physical conditions (sometimes known as **co-morbidity**). Epilepsy is fairly common, especially in those with 'classic' autism. Depression is also very common, as is dyslexia, although it is not clear if the incidence of these is greater than in the non-autistic population.

Activity 4 Why is autism a spectrum?

Allow about 15 minutes

Now that you have been introduced to some key facts about autism, write a few notes commenting on why it is considered to be a spectrum. For instance, how much does autism vary between people?

Provide your answer...

Answer

How do your notes compare with our feedback below? Have you included some of the same ideas?

Although people meeting the diagnostic criteria for autism share characteristic difficulties in social interaction, and the tendency to repetitive or restricted behaviours and interests, these are expressed in different ways and to different extents. One person may speak very little, while another speaks a lot, perhaps not taking the interests of listeners into account; one person may be particularly sensitive to loud sounds, while another has heavy metal music as a special interest. This variety in behaviour, and the genetic and biological variability which underlies it, has meant that the concept of autism has evolved from the original idea of a specific syndrome, to that of a spectrum.

Note that the concept of a spectrum derives from the physics of white light which is made up of an array of colours ordered from low frequencies (red) to higher frequencies (violet) as can be seen in a rainbow. But borrowing this concept has led to the misleading idea that autism is a linear scale with profoundly affected individuals at the 'low' end and less affected individuals at the 'high' end. In practice, a person with good intellectual and language skills, often known as **high-functioning**, may nevertheless be profoundly disabled by repetitive behaviours and routines which challenge daily living skills. So the autism spectrum needs to be thought of in more complex terms. In this 'infinity spectrum' one individual could be in the 'high' or violet area for intellectual skills, have moderately good language and communication skills (green) but be in the 'low' or red area for daily living skills.

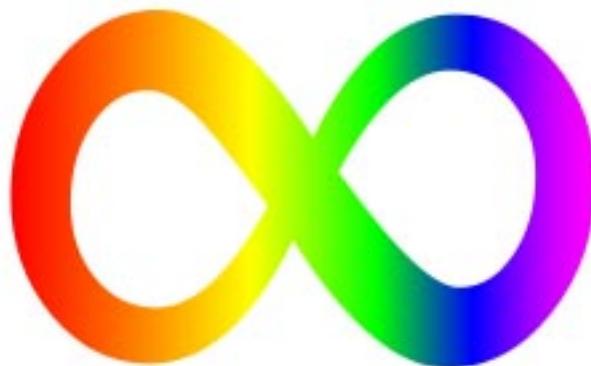


Figure 1 Autism spectrum infinity awareness symbol.

3 Sources of knowledge

How have your initial ideas about autism compared to what you have read so far? You may have been pleased to have your ideas confirmed, or surprised by what you didn't know. As you will see, it is also important to think about where your initial ideas came from.

Activity 5 Information about autism: reliable or not?

Allow about 15 minutes

Think now about the sources of your ideas about autism when you started the BOC. Did they come from articles or books you have read, films, the internet, or other sources? Spend a few minutes noting what your sources were, and for each source, how reliable you think the information would be.

Provide your answer...

Answer

Did you mention any of the following?

- the internet
- other media such as newspapers/radio
- fictional stories and films
- theatre
- television documentary
- factual books
- personal acquaintance
- published autobiographies and parental accounts of autism
- academic articles
- conferences and lectures.

Although ‘popular’ sources such as the internet, newspapers and radio can be useful, the claims they make are not subject to the same standards of verification that are required for claims based on research or clinical practice. Fictional sources such as the theatre, books and films can also be helpful in bringing conditions like autism to public attention. But there is no requirement to be ‘true’ to the condition, and directors may choose to emphasise or exaggerate particular aspects for dramatic effect. Knowing an autistic person is obviously an extremely good way to gain understanding, but since each autistic person is different, knowledge derived in this way may not be representative of everyone on the spectrum.

Much of the reliable information that we have about how and why autistic people differ from the **‘neurotypical’** (non-autistic) population comes from clinical and research work, which is spread through academic conferences and lectures and published in academic journals and books. These sorts of sources were used for the quiz answers earlier. Two more very important sources for understanding what autism is like are personal testimonies by individuals with autism and their parents and carers. Again, however, individual or parental accounts may not be representative of everyone on the spectrum.

In the next section you will read about the different methods used by researchers and clinicians to derive evidence about autism. Following that there will be some personal testimonies from autistic people and from parents.

4 Methods for understanding autism

Claims about autism should be based on the careful and balanced evaluation of evidence derived from reliable sources. There are many different ways of obtaining evidence, and no one method can provide all the answers. Key methods, as discussed in this section, typically involve studying autism from an '**outside perspective**' – that is from the stance of the clinician or researcher. In the next section you will consider insights from the '**inside perspective**' – from personal accounts by autistic people or close family members.

Clinical and research methods may also involve working closely with autistic individuals and their families to gain more of an 'inside view'. Consequently 'outsider' and 'insider' approaches are not always clearly differentiated.

4.1 Case studies and observational methods

The **case study** method, most often used by clinicians, involves careful, detailed observation of individuals (autistic children in this case) over a period of time, together with in-depth interview with the individuals, or with other family members. The clinician uses their expertise to interpret observed behaviour and other signs as carefully and objectively as possible in order to formulate detailed individual reports. But the choice of which individuals and which behaviours to observe, and the clinician's own assumptions and expectations may nonetheless serve as sources of bias. Fully fledged **observational methods**, often used in research studies, may involve further steps to control or minimise such biases.

In a typical investigation, observations of a group of autistic individuals will be compared with observations of a comparable group of neurotypical people (people without autism). The neurotypical comparison group, known as a **control group**, is matched as closely as possible to the autistic group in terms of factors such as age, intellectual level and language ability. Thus any differences that emerge between the autistic and control groups can be attributed to autism, not some other group difference, such as age.

Matching by age might seem straightforward, but is usually not sufficient to make a fair comparison, since autistic people may have language difficulties or be intellectually less able than neurotypical people of the same age. Specialised tests of language ability and/or intellectual ability (IQ), part of a systematic method known as **psychometrics**, are used to measure the functioning of those in each group. Psychometrics means the objective measurement of psychological abilities and traits, and includes tests of skills and knowledge, abilities, attitudes, personality traits and so on.

Other means to avoid observational bias may include an agreed observation schedule to avoid the researcher picking out just what appear to be the most significant behaviours, and '**blinding**', a procedure in which those making and interpreting the observations are not told which participants have autism and which are neurotypical.

4.2 Experiments

The **experiment** is a method which builds further on the systematic, controlled approach just described. Experiments are typically used to gain insights into how people deal with the world around them – for instance, how they remember information, attend to things, or

recognise people's faces. Experiments put claims such as 'individuals with autism have very good memories' to a critical test, so countering false or misguided opinions.

Say that a researcher sets out to explore memory ability in autistic people. Firstly a **hypothesis** is formulated. This might state, for instance, that memory for words or faces will differ between autistic and neurotypical people. An experimental group of autistic people and a matched neurotypical control group will take part in a memory test: for instance, seeing or hearing a list of words and recalling them after an interval. The number of words recalled by each participant would be one simple measure of their memory in this task. From this the researcher calculates the average score for each group and compares them. Statistical tests are used to evaluate the probability that any apparent difference between the groups has occurred by chance. A result that is highly unlikely to have occurred by chance is said to be **statistically significant**, enabling a reasonably confident conclusion that the hypothesis has been confirmed.

The same basic framework can also help determine whether or not an intervention (treatment) is useful, by comparing changes in a group of autistic children receiving the intervention with an age- and intellectually-matched group of children also with autism, but not receiving the intervention.

4.3 Brain imaging

Much of the evidence for differences in the brain in autistic people comes from **brain imaging** methods. Some – for instance **Magnetic Resonance Imaging (MRI)** – are used to explore whether there are differences in brain structure. Others, for instance **functional Magnetic Resonance Imaging (fMRI)**, are used to explore brain activity while a person performs experimental tasks such as recognising faces.

4.4 Longitudinal studies

All the methods mentioned so far – case studies, observational studies, experiments and brain imaging – can be repeated at intervals. So, for instance, behaviours in a particular group of children may be tracked over a number of months or years. Following the progress of individuals or groups over a time period like this is called a **longitudinal study**.

4.5 Twin studies

Another important method for autism research is the **twin study**. This involves comparing identical twins, who originate from a single fertilised egg and have identical genes, with non-identical twins, who come from two different eggs and who, on average, share 50% of their genes – just as siblings do. This type of study regularly finds that when one member of an identical twin pair has autism, the second twin is more likely to have some form of autism than when the twins are non-identical, providing evidence of a strong genetic influence. Studies of both twins and wider family members have shown that autism is highly heritable, meaning that genetic factors play a major role in determining whether individuals within a population will develop autism. However, this **heritability** is very complex. For instance, while some genetic variations linked to autism are ones that offspring inherit from their parents, others may arise afresh, affecting just one individual or

a pair of identical twins within a family. Some non-genetic factors may also contribute to causing autism. These complex factors are further discussed in section 5.3.

4.6 Surveys and questionnaires

Surveys and questionnaires are ways to obtain a relatively large sample of opinions, attitudes or preferences. The methods involve standardised questions (written or verbal) exploring topics such as what parents and autistic people think about the support which is available to them. This information is then analysed statistically to obtain a representative picture of the responses.

5 Personal testimonies

While not everyone with autism is able to describe their experiences, an increasing number of personal accounts provide insights which both complement and differ from 'outsider' insights. Parents may also provide deep insights which are not available without these close bonds. Remember, though, that individual accounts of autism are just that. For instance, some autistic individuals describe their thinking style as highly visual. But this does not necessarily mean that visual thinking is a general trait in autism. Next you will consider some parental and personal accounts.

Activity 6 Learning from personal accounts

Allow about 20 minutes

Read these two passages and listen to the interview extract. Make a few notes on similarities and differences between the accounts. For instance, are the accounts given by autistic individuals or by parents? What interests and difficulties do they talk about?

Jessy's social understanding remained, and remains, radically incomplete. Such simple lessons. 'We can't ask them to move because they were there first.' The difference between irritation and hurt feelings. Making sense of people, 'grasping the general significance of situations'. What the autistic adult, like the autistic child, finds hardest of all.

What is it like to have a mind that picks 'remembrance' out of the newspaper yet must struggle to comprehend the most ordinary vocabulary of social experience? What is it like to have to learn the myriad rules of human interaction by rote, one by one? By rote, because the criterion of 'how would I feel if' is unavailable, since so much of what pleases (or distresses) her, does not please others, so little of what pleases (or distresses) others pleases her.

Clara Claiborne Park writing about Jessy, aged 42 (Claiborne Park, 2001, pp. 16–7)

I must mention that the boy loved to watch the different calendars of different rooms and then recall the numbers. He also compared them. He thus spent a lot of time, gazing at the numbers. He wanted to know what they meant. He found a kind of pattern in them. He wondered how the figures bent and straightened up, curled and sometimes broke!

Tito Mukhopadhyay aged 8, writing about himself as an infant (Mukhopadhyay, 2000, p. 19)

Listen to the following extract from a recorded interview with Dr Wenn Lawson discussing his autism with Dr Ilona Roth (Lawson and Roth, 2011). Note that Wenn was living as a woman at the time of this interview.

Audio content is not available in this format.

Answer

Tito Mukhopadhyay (a young boy in 2000) and Wenn Lawson (an adult) contribute their personal reflections, while Clara Claiborne Park speaks for her adult daughter Jessy.

Tito and Wenn Lawson mention passionate engagement with particular topics (calendars, numbers, insects, machines) while Clara mentions Jessy's attention to detail.

Clara Claiborne Park and Wenn Lawson both mention problems and frustrations of understanding the subtleties of language, the rules governing social situations, and the difficulty of taking other people's feelings into account.

Finally, in this clip meet Alex, who will describe his experiences of autism at various points in the module.

Video content is not available in this format.

6 Brief history of autism: key players and milestones

We will end this introduction to autism with some historical background. Autism was first described in the early 1940s, and with developments in knowledge, the concept has been evolving ever since. To understand where we are now, it is important to know something about the key players and historical milestones of the last 8 decades.

Some of the language and concepts for describing and discussing autistic people throughout history may now seem odd or completely unacceptable. Remember, though, that ideas about autism arose within the context of psychiatric thinking and social attitudes of the time. Even if some of these ideas now seem misguided or wrong, their role in the history of autism must be understood and acknowledged.

6.1 1940s: the pioneers

Leo Kanner, an Austrian-born immigrant to the USA, pioneered the application of psychiatry (the branch of medicine that deals with the mind) to psychological problems in children. In 1943, he published one of the first known accounts of autism, based on his case studies of 11 children referred to his clinic (Kanner, 1943). He identified language problems; atypical use of non-verbal communication, such as eye gaze and gesture; narrowly restricted interests and a desire for sameness; and atypical reactions to sensory stimuli. The children's apparent aloofness and isolation from the human world led him to coin the phrase 'autistic aloneness'. 'Autism' comes from the Greek word 'autos' for self, and means being absorbed into oneself. To Kanner these shared features of behaviour suggested a **syndrome**, a specific disorder with a characteristic set of **symptoms** (observable characteristics that may indicate a clinical problem or disorder). Even today Kanner's descriptions of autism remain remarkably fresh and up to date. However, these days the varied profile and severity of key symptoms between individuals is considered to represent a spectrum of problems rather than a single unified syndrome



Figure 2 Leo Kanner 1894-1981

The second autism pioneer was Hans Asperger, a paediatrician working in Vienna during the same period as Kanner was active in the USA. In a paper published in German, Asperger described a behaviour pattern very similar to Kanner's description, which he called 'autistic psychopathy' (Asperger, 1944). 'Autistic', as for Kanner, referred to the children's aloneness and self-absorption, while by 'psychopathy' Asperger meant a psychiatric disorder affecting the personality. Asperger highlighted important features in common with Kanner's case studies, yet the children he described seemed less disabled than Kanner's group, generally having fluent speech and vocabulary, even if they used it oddly. They tended to talk at length about their favourite topic or interest. Rather than seeming unaware of the existence of others, their reactions to others appeared strange and antisocial. Asperger's work was for many years not widely known outside Austria. It was only in the 1980s that psychiatrist Lorna Wing highlighted the remarkable similarity between Asperger's and Kanner's clinical observations and 'Asperger syndrome' was recognised as a diagnostic sub-type of autism. Wing also introduced the term 'autism spectrum' to reflect the variation on the core symptom profile.



Figure 3 Hans Asperger 1906-1980

6.2 Asperger revisited

Until very recently, many believed that Asperger shielded children in his clinic from Nazi programmes designed to ‘cleanse’ the Austrian and German population of individuals deemed to be weak, burdensome or ethnically non-Aryan (e.g. Jewish). However, very recently two researchers have shed new light on Asperger’s war-time activities (Czech 2018; Sheffer 2018). They provide convincing evidence that Asperger collaborated with the Nazi regime, despatching some children in his care to a ‘euthanasia clinic’ where they met their death. These revelations have caused widespread shock and revulsion, and at the time of launching this course, Asperger’s standing and contributions to the autism field are under searching review. There is no simple way forward. For instance, although Asperger syndrome is, for other reasons, ceasing to be a formal sub-diagnosis, for several decades, many people on the autism spectrum have accepted Asperger syndrome as their diagnosis, and embraced it as an identity. A range of views is beginning to emerge: some are arguing that Asperger syndrome should be renamed; others point out that history cannot be completely rewritten and terminology should be considered distinct from the individuals who may have originated it.

You can read more about the researchers’ findings and about different ideas for the way forward here:

<https://www.spectrumnews.org/news/new-evidence-ties-hans-asperger-nazi-eugenics-program/>

6.3 1960s: biological and socio-emotional theories of autism

Kanner initially favoured a **biological explanation** of autism (an atypicality in brain function). However, he began to consider autism as a form of withdrawal from the emotional coldness he had perceived in some mothers. This **socio-emotional explanation** of autism was probably influenced by the early 20th century popularity of Freudian psychoanalysis in the USA, which saw children's personalities as strongly influenced by their early experiences with their parents. Although Kanner later retracted this idea, it was enthusiastically promoted by the psychoanalyst Bruno Bettelheim who, in the 1960s, practised a treatment in which children with autism were separated from their parents to live in a special 'therapeutic' environment (Bettelheim, 1967). He described apparently dramatic improvements in the emotional adjustment, speech and behaviour of children treated in this way, but his claims were subsequently discredited.

Many parents were extremely upset by the poor parenting theory. The psychologist Bernard Rimland noted that while his wife was an affectionate mother, their son screamed constantly and inconsolably from an early age. Rimland began to collect scientific and medical evidence to challenge Bettelheim's approach, publishing his own biological theory of causation (Rimland, 1964). He devoted his life's work to autism, acting as an advocate for children with autism and founding the Autism Society of America in 1965.

6.4 1960s: developments in the UK

In 1962, a group of pioneering UK parents founded the **National Autistic Society (NAS)** to campaign for better services and support for autistic children. Their first school, run by Sybil Elgar, was established in 1965. Elgar pioneered a teaching method using a structured environment, clear and straightforward communication and visual aids. The NAS has since become a major source of information, advice, services and resources, and notably campaigns for the needs of adults with autism to be recognised and addressed.

6.5 1970s: early research milestones

Some of the first experimental studies of autism were conducted in the 1970s by the psychologists Beate Hermelin and Neil O'Connor, who developed a framework for studying many aspects of sensory, perceptual and memory processing (Hermelin and O'Connor, 1970).

Later in the 70s, Susan Folstein and Michael Rutter carried out their pioneering twin study (Folstein and Rutter, 1977). Folstein and Rutter found that when one member of an identical twin pair had autism, the second twin was more likely to have some form of autism than when the twins were non-identical. The researchers interpreted this as strong evidence that autism has a genetic basis.



Figure 4 Sir Michael Rutter b.1933

6.6 1980s: an intervention to help children with autism

An influential early development in therapeutic **interventions** adopted the idea that autistic people have acquired, through learning, a set of 'maladaptive' or inappropriate behaviours, which can be eradicated or 'retrained'. The psychologist Ivar Lovaas pioneered **behaviour modification** techniques for children with autism, using rewards to encourage 'desired' behaviour such as language and to discourage 'difficult' behaviours (Lovaas, 1987). While these days some practitioners are highly critical of behaviour modification, arguing that it does not address the underlying psychological difficulties, approaches based on Lovaas' ideas are still in use. Other approaches which aim to tackle the core problems more directly may nonetheless incorporate the basic principles of behaviour shaping.



Figure 5 Ivar Lovaas 1928-2010

6.7 1980s–90s: a new theory of autism

In 1985 three psychologists, Simon Baron-Cohen, Uta Frith and Alan Leslie, published an experimental study suggesting that children with autism have difficulty understanding what others are thinking and feeling – a '**Theory of Mind (ToM)**' difficulty (Baron-Cohen, Leslie and Frith, 1985). This finding stimulated a huge wave of further research, throughout the 1990s and to the present day. Though by no means the only new theory proposed during this period, and much modified, it is still influential. You will come across it later in the course.



Figure 6 Simon Baron-Cohen b.1958



Figure 7 Uta Frith b.1941

6.8 1960s–2010s: prevalence of autism in the population

Prevalence means the number of individuals affected by a condition at a given time. Measuring autism prevalence depends on estimating how many individuals in a population have a symptom profile that fits the diagnosis. When autism was first identified it seemed to be rare. In 1966, Lotter estimated that childhood autism affected 4 children in 10,000. In the late 1970s, and adopting a wider definition of autism, Lorna Wing and Judith Gould (Wing and Gould, 1979) scrutinised the medical and social services records of 35,000 children in Camberwell for likely cases of autism. Their prevalence estimate was 21 children in 10,000, of whom 5 would have ‘classic autism’, while the rest were somewhere on a ‘spectrum’ – which was becoming an increasingly relevant concept to all working on autism. Notice how prevalence estimates changed as the definition of autism (i.e. the inclusion criteria) was broadened. With further research and clinical advances leading to even broader criteria and more widespread diagnosis, it is currently estimated that at least 1 in 100 individuals in the UK may be on the autism spectrum. A recent worldwide estimate, based on prevalence studies in different countries, is somewhat

lower. But where awareness of autism and diagnostic services are limited, estimates of prevalence are inevitably lower. For some parts of the world (for instance many African countries) where diagnosis is barely available, prevalence cannot be reliably estimated. You will read more about this in Weeks 3 and 8.

6.9 1986 onwards: autistic people speak for themselves

The dominant image of autism up to the 1980s was that of a person lacking the self-insight and communicative skills necessary to tell others what it is like to be autistic. This perception was challenged when an American professor called Temple Grandin published a book about her experience of autism (Grandin and Scariano, 1986). As a child in the 1950s, Temple's delayed speech development and odd behaviour were attributed to brain damage. Her mother resisted attempts to have her institutionalised and hired a speech therapist. At school Temple benefitted from the encouragement of some wise mentors. When she was 18, her mother happened upon Bernard Rimland's work and realised that her daughter was autistic. Temple nonetheless went from strength to strength, studying at university and becoming a professor and world expert on livestock handling, as well as a spokesperson on autism. Since Temple's pioneering effort, many other personal accounts of autism have been published.

6.10 1990s onwards: the neurodiversity movement

Once people like Temple Grandin had found a voice and an audience, other challenges to the image of autism as a disabling medical condition started to occur. **Neurodiversity** refers to the idea that a neurological condition such as autism is simply one form of variation between individuals, not a fundamentally different or pathological category (Blume, 1998). This goes hand in hand with the idea that autism does not need treatment or a cure. Not everyone agrees with this view: many families where an individual is profoundly affected by autism do see autism as disabling, seek treatment, and argue that those advocating neurodiversity do not speak for everyone on the autism spectrum.

6.11 The autism spectrum in the 21st century

The many developments in the autism field since the year 2000 make it hard to select the most important 'players' and milestones. You will learn more during the rest of this course. In research, advances in brain imaging and human genetics have shed new light on the brain systems and genetic mechanisms that may be involved. There is no 'cure' for autism, and some reject the very idea of a cure. But a range of helpful interventions is available, thought to be especially effective if started early. Revised diagnostic criteria for autism published by the American Psychiatric Association (American Psychiatric Association, 2013) addressed some of the inadequacies of earlier versions. Yet there is growing concern that autism in women may present in atypical ways and is going undiagnosed. Progress in autism rights includes, in the UK, the 2009 Autism Act, responding to an NAS campaign to protect the interests and address the needs of autistic adults. In 2014 the 67th World Health Assembly of the World Health Organisation passed

a resolution supported by 60 member states to coordinate their efforts in addressing autism worldwide.

7 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 1 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

8 Summary

This introductory week of the course has provided you with an overview of autism, highlighting key facts, and also just how much remains to be discovered. You have seen how the concept of autism has evolved since Kanner's and Asperger's early work, and in light of the variability which has emerged, how autism has come to be known as a spectrum. The importance of basing claims about autism on reliable sources of information has been demonstrated. Systematic methods such as experiments and surveys play a key role in furthering knowledge; insider accounts by people on the spectrum are also crucial in enhancing understanding. You will have noted that some ways of discussing, explaining and engaging with autism are highly contested, especially concerning whether it is a disorder, condition, or just a form of neurodiversity, and the related issue of whether autistic people need to be 'cured'.

You should now be able to:

- evaluate and update your own knowledge of autism
- express a general overview of autism and why it is considered a spectrum
- understand different ways of gaining evidence and insights into autism
- appreciate some different experiences of autism
- understand key milestones in autism history.

Next week you will look at the different features of autism in more detail, giving particular attention to characteristic profiles of difficulties and strengths, to difficulties which may accompany autism, and to how things may change as children develop.

Now you can go to Week 2.

Week 2: What is autism like?

Introduction

By now you should begin to have a fair picture of autism. This week looks in more detail at key characteristics, giving particular attention to difficulties and challenges, and also to strengths, and to how these may vary between individuals and groups.

Now watch the video in which Dr Ilona Roth introduces this week's work.

Video content is not available in this format.

By the end of this week you should be able to:

- formulate a more detailed picture of autism characteristics and the challenges they may pose for the individual and their family
- have insights into autistic strengths, including special skills and outstanding talents
- appreciate ways in which the profile of difficulties and strengths varies between different individuals
- understand that the autism spectrum encompasses striking IQ differences between individuals
- recognise the presence of accompanying problems such as epilepsy or dyslexia in some cases.

1 Autistic traits and neurotypicality

As you saw in Week 1, autism involves characteristic traits – ways of behaving and interacting with the world – which differ from those of the neurotypical population.

Given the varying pattern and impact of these differences in autism, specialists need clear and explicit criteria to evaluate whether, say, one person's limited use of spoken language and another person's excessively verbose speech both 'tick the box' for an autism-related symptom. Diagnostic criteria are developed, piloted and refined over a period of years by specialist working groups. You will explore them in more detail next week. Meanwhile, watch this clip in which Arabella describes how she came to realise that her daughter, Iris Grace, might be different from other children.

Video content is not available in this format.

2 Social characteristics

Common social differences between young children with autism and **typically developing (TD)** children might include a lack of the spontaneous showing and pointing by which TD children share their interests with others, or not following what others are attending to, known as **joint attention**.

2.1 Interacting and communicating non-verbally



Figure 1 This small boy points to indicate something in the sky that interests him, and to engage his mother's attention in the same object. Children with autism often lack this kind of pointing and drive for joint attention.

At the age when typically developing children start to play together and make friends, an autistic child may prefer to play alone; the play may seem rigid – for instance a child may prefer to line up his play figures rather than using them for a pretend game, such as a tea party.



Figure 2 Children with autism often seem happiest playing alone, rather than joining in with other children.

Further differences that may impact on social interaction at any age include problems with **non-verbal communication**, such as using or understanding gestures and facial expressions, making eye contact with others, and judging subtle aspects of **body language** such as how close it is acceptable to stand to a person you don't know. There may also be a lack of emotional 'give and take', such as not responding to the changing emotions of other people.

2.2 Communicating with language

In autism, difficulties in using language for communication range from the total absence of speech (without the use of gestures to compensate) to the use of language that is excessively repetitive or unusually stereotyped. Some may only speak in certain circumstances, such as with people they know very well. This is known as **selective mutism**. Speech may also seem unusual to others in terms of qualities such as **intonation** (the way it rises and falls), **pitch** (whether the speech is high or low) and **stress** (the use of emphasis to mark particular words or phrases).

Even when an autistic person has fluent language, there are likely to be other problems of communication, such as difficulty in taking turns when talking to others. **Turn-taking** –

where one person speaks and then listens to what another has to say in response – is fundamental for dialogue or two-way conversation. Without this skill, an autistic person may constantly interrupt when others are talking, or deliver long monologues on a subject which fascinates them, without noticing whether this is of interest to those listening.

2.3 Taking things literally

Another noticeable language difference is taking the meaning of words, phrases and sentences literally – for instance a child told ‘pull your socks up’, meaning ‘try harder’, may assume that it is their socks which need attention. When an autistic boy called Michael Barton was at junior school, he devised a strategy to help him decode the non-literal expressions that he found so strange. He would note the expression and draw a picture of it, followed by a sentence explaining what it meant. As a young adult he has published his delightful drawings to help others on the spectrum (Barton, 2012).

His head is in the clouds



He's daydreaming

Figure 3 'His head is in the clouds' by Michael Barton.

Activity 1 Misunderstanding what people say

Allow about 5 minutes

In this clip a young man explains why taking things literally can make it difficult to understand jokes. Watch the clip and then write a few notes explaining how an ironic or sarcastic comment might lead to a similar misunderstanding (hint: think about the words and the tone of voice when a person says something sarcastic).

Video content is not available in this format.

Provide your answer...

Discussion

When a person speaks ironically or sarcastically, they may say one thing, but in a tone of voice which indicates that they mean something else. For instance 'It's a really nice day today' when it is actually pouring with rain, or 'You are so good at English' when it is a field that the person struggles in. An autistic person listening to such a comment may take it literally, and not notice or understand the non-verbal cues provided by the tone of voice, which indicate that the speaker means something different from what he or she says.

Literal-mindedness can also mean that an autistic person says things which others find rude or hurtful, because they don't realise that being completely truthful and candid isn't always polite. For instance, telling someone who has just cooked you a meal that you don't like their food is not usually the best approach if you are invited for dinner. In general, autistic people tend to lack intuitive understanding of the unspoken social rules that apply to different situations, leading to social 'faux pas' or blunders. This lack of insight into other people's thoughts, feelings and points of view is often thought of as a 'Theory of Mind' failure, a psychological concept which will be covered in Week 4.

To gain an insight into how an autistic person may quite unintentionally upset others by failing to understand social rules, watch the two video clips below.

Video content is not available in this format.

Video content is not available in this format.

2.4 Socialising

Finally, autistic people may not always value socialising as much as others. Children in particular may react strangely to things like birthday parties and Christmas gatherings of family, finding the changes to normal routine, the comings and goings and the surprise of presents overwhelming. Yet autistic people can still experience loneliness. It should not be assumed that they want to be left alone, but they may need help to socialise, and also 'recovery time' from socialising, since constantly trying to work out the meaning of what others say and do can be exhausting and stressful.

For further discussion of social and communication characteristics in autism, see Roth et al. (2010), chapter 3.

3 Non-social differences

3.1 Repetitive behaviour and routines

Some children incessantly twirl their fingers or flap their hands. Such movements are often known as **stimming**, because they may play a role in changing sensory stimulation. For instance, moving the hand up and down in front of the face may cause a pleasing change in the pattern of light reaching the eyes. Children may also develop intense preoccupations and obsessions with specific objects or textures, such as running their hand up and down a velvet curtain. They may line up their toys in a repetitive or obsessive way, or insist on wearing the same clothes or eating the same food every day. They may become anxious and distressed if a familiar routine, such as going to school by bus, is disrupted.

3.2 Special interests

Many autistic people, both children and adults, develop an extremely intense **special interest** in a particular topic, sometimes becoming so absorbed that they fail to do other things, including eating and sleeping! Sometimes, the interest topic itself may not seem unusual, but what sets it apart is how strongly and for how long it is pursued. For instance, many young children love Thomas the Tank Engine, but they may not watch their favourite episodes incessantly and to the exclusion of any other children's programmes, or still watch them when adolescent. Some autistic special interests are markedly different from those that most people favour as hobbies and leisure pursuits, focusing on unusual topics such as washing machines, or the Titanic passenger list, for instance.

Neurotypical people may struggle to understand the attraction of these unusual special interests, and parents may express frustration at the amount of time their child spends on their interest to the exclusion of other activities, and at the incessant questioning that may accompany it. Some autism practitioners argue that special interests are detrimental because they exacerbate social isolation and suppress other opportunities for learning. Yet the individual with the interest may find their chosen pursuit fulfilling and comforting (Grove, Roth and Hoekstra, 2016), and other practitioners believe that special interests can serve as effective building blocks for learning. For instance, teachers can make use of the special interest to develop reading, writing and other skills, or simply as rewards for attending to other tasks. Finding others who share the same interest may also lead to developing a circle of friends. There is much still to be explored in this field.

Activity 2 Special interests

Allow about 10 minutes

Read the two extracts in which autistic people describe their special interests. Do you find anything unusual about these interests – either the topics, or the way they are pursued? Make a few notes.

In fourth grade, I was ... interested in both dinosaurs and astronomy, especially since this was the time of the Voyager flybys of Jupiter and

Saturn. My appetite for information was voracious and I would clip or photocopy everything I could find on the subject in the newspaper, magazines, academic journals and books. I think my interest in dinosaurs waned at this point, though I remember an occasion when I went to the neighbourhood pool and I went up to total strangers asking them to ask me any question about dinosaurs because I felt I knew everything about them.

Sarah quoted in Sainsbury, 2000, p. 68

My parents and my family weren't really into reading and the sorts of things I was interested in so it was difficult and it was hard for my family to appreciate the passionate way that I got involved with things. They didn't understand why anyone would want 100 mice, for example, little white mice with purple eyes that I bred in Smiths Crisp tins covered with chicken wire in the garage, and they didn't understand why I collected beetles or why I would line up my insects and race them. My sisters wouldn't do those sorts of games, they played tea parties and dolls houses and I wasn't interested in those sorts of things.

Lawson and Roth, 2011

Provide your answer...

Answer

The first extract describes special interests which many other people share. But the engagement with the interest is very intense, and the attempt to involve strangers in 'quizzing' the writer is perhaps unusual.

The second extract describes passionate involvement in various interests, including mice. Keeping one or more mice as pets would not be that unusual as a childhood interest. But Wenn's interest focused on one particular kind of mouse, and breeding lots of them suggests a strong drive to collect things, which Wenn acknowledges in his reference to beetles. Again, there is an intense and somewhat unusual way of engaging with several topics of interest.

3.3 Unusual sensory responses

For many people on the autism spectrum, sensory information (received via eyes, ears, touch etc.) evokes either stronger or reduced responses compared to neurotypical individuals. For instance, autistic people may dislike fluorescent lighting because they can perceive the flicker. This dislike can be so intense that they will refuse to enter a room with that type of lighting. They may need labels cut off clothes as they find the sensation unbearably irritating. One of the reasons Temple Grandin gives for wearing her distinctive cowboy-style shirts is that they are made in very soft cotton, the only texture she says she can tolerate next to the skin. Such accentuated reactions are known as **sensory hypersensitivity**.



Figure 4 Temple Grandin wearing one of her soft cotton cowboy shirts.

Profound aversion to the taste or smell of particular foods is also common, and yet some autistic children seem to crave particular tastes such as sugar. Similarly, when it comes to sound, one person may find the noise of traffic in the street unbearable, but another may seem immune to the noise. Apparently lowered responsivity to sensory stimuli is known as **sensory hyposensitivity**. For instance, an autistic person may tolerate or enjoy the sound of vacuum cleaners, or heavy metal music played at exceptionally high volume, oblivious to the disagreeable effect on others, or the possible damage to their own hearing. The pattern of these sensory differences may also change over time.

Listen to this clip of Arabella, mother of Iris Grace, discussing how Iris Grace's sensory responses fluctuate and change over time.

Video content is not available in this format.

4 Reactions to stress

Autistic people may experience enormous stress and anxiety as a result of any of the traits just described. Social situations, the disruption of familiar routines and activities, or exposure to aversive sensory stimuli such as textures, smells and sounds, may be confusing, overwhelming or even frightening. In such situations, both children and adults with autism may resort to activities or behaviours which seem particularly unusual to others, but which help the person to manage and reduce the stress they are feeling.

Listen to Arabella again:

Video content is not available in this format.

Sometimes, in response to an unbearable level of stress, an autistic person may have a '**meltdown**'. This may look like a temper tantrum, but is an expression of distress and overwhelm, with the added frustration that the person may be unable to communicate this.

During our first hour on the road, Elijah rifled through hundreds of stickers I had brought along to keep him busy in the car. He feverishly peeled them and pasted them onto a large piece of cardboard like a small machine with his strict and narrow concentration. In the rear-view mirror, I saw the waxy paper backings of the stickers piling up in the back seat like fluffy patches of snow surrounding him. When he had peeled the very last sticker from its paper he let out a screech. Quickly, I popped the Pinocchio soundtrack into the tape player to redirect him, but to my dismay, I had forgotten to rewind it.

... 'REEE...WIND' he bellowed when he suddenly heard Pinocchio's voice singing mid-song.

Valerie writing about her son, aged 5 (Paradiž, 2002, p. 132)

Stress reactions are likely to happen regardless of the person's level of functioning. For instance, high-functioning teenagers with all the intellectual skills necessary to attend university, are quite likely to struggle with living away from home, dealing with personal care and the constant pressure to socialise. It is important that their tutors or mentors are aware of the additional emotional strains they are under, and that the university has support strategies in place.

5 Skills and talents

While some aspects of autism undoubtedly present difficulties or challenges for the individual, you have seen that others may simply be unusual such as an eccentric special interest. Some autistic people also have enhanced skills, such as very good numerical or mathematical skills, excellent memory for names or facts, or enhanced visual and spatial skills. Since such skills often exist alongside marked difficulties, they are sometimes called '**splinter skills**', meaning that they do not generalise well to other tasks.

5.1 Skills

Often the same autistic characteristic which can make life difficult in some situations – for instance, the tendency for **attention to detail** – has positive sides in others. An autistic person trying to describe the main features of a picture or diagram, or to summarise the general storyline of a film, may go into all the details, and thus be unable to give a concise overview. This can be problematic, especially in education, where the skill of summarising key points is important. However, noticing details can also be a valuable skill. For instance, a recent report describes how autistic employees are helping banks to detect fraud and money-laundering, with their ability to detect subtly unusual patterns in large data sets (Hickey, 2015).

Another example is the need for structure, routine and repetition. Difficulty adapting to change may go with the capacity to persist in tasks for which others would not have sufficient patience or attention span. Again, this is proving invaluable in some industrial jobs.

The same social naivety which, as we saw earlier, may lead a person into awkward social situations, means that autistic people tend to speak their mind with great honesty. In a world where some people resort to dishonesty and deception to get what they want, such honesty can and should be highly valued. An employer, for instance, may place particular trust in autistic staff members.

5.2 Exceptional talents

While pursuing their special interest (see the previous section), an autistic person is likely to develop an exceptional knowledge or grasp of their favoured topic and so become an expert. A minority of autistic people show truly **exceptional talents**, which typically appear in early childhood, often without prior learning or practice.

For instance, Stephen Wiltshire did not speak until he was 5 years old, and was diagnosed with autism. But he showed an outstanding talent for drawing from an early age, and without being taught. Ever since then he has been drawing complex cityscapes such as Canary Wharf, producing impressive and astonishingly accurate works after just a few minutes studying the subject matter.



Figure 5 Canary Wharf by Stephen Wiltshire, 2006.

Watch these clips to learn more about the work of talented autistic artists.

1. Stephen Wiltshire and his sister talk us through as he makes a drawing of New York City.

<https://www.youtube.com/watch?v=bsJbApZ5GF0>

2. Iris Grace is another extremely talented artist, whose talent just took off when her mother bought her some paints. Here she is shown aged 3, working on one of her colourful paintings.

<https://vimeo.com/134532771>

3. Derek Paravicini displayed a similar early and self-taught talent for the piano. As an adult he has an impressive musical repertoire, is an accomplished jazz pianist and has played with Jools Holland among others. Here he improvises on a well-known Brazilian melody.

<https://www.youtube.com/watch?v=Ti2xi48WCMQ>

Such exceptional talent, surpassing that of most neurotypical people and coupled with fairly profound difficulties, is often known as **savant talent**. As in these examples, it often involves visual art or music, though savant talent may also involve domains such as calculation, as portrayed in the film *Rain Man*. Note that Dustin Hoffman's character Raymond had difficulty with everyday transactions despite his specific calculating skills.

5.3 Creativity

Researchers seeking to explain the basis of exceptional savant talents have suggested that the key underlying abilities are exceptionally accurate memory and attention to detail rather than the ability to generate truly original outputs (Treffert, 2006). This is in keeping with a traditional view, emphasised by the diagnostic criteria, that autistic people lack

creativity. However, it is becoming clear that autism is compatible with creativity and may even promote it (Roth, 2007; Treffert, 2009). The American artist Jessica Park makes pictures of well-known buildings which are accurate and yet highly original in their imaginative use of colour.

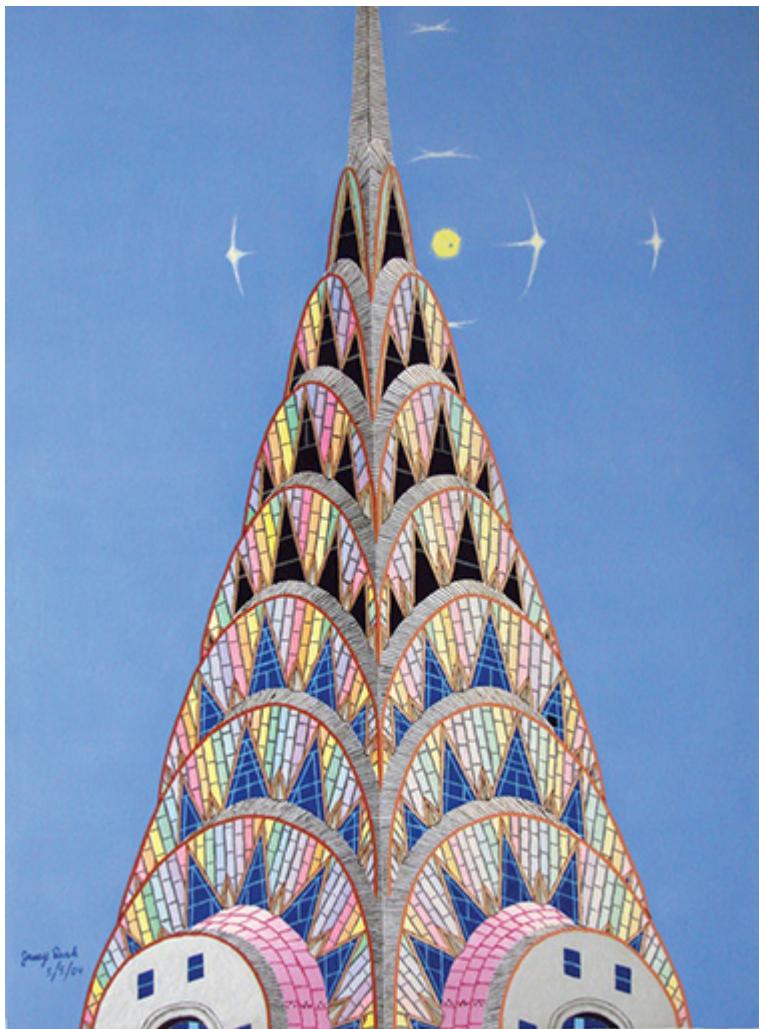


Figure 6 Jessica Park's picture of the Chrysler Building, New York.

The autistic artist Jon Adams, who was diagnosed with Asperger syndrome as an adult, reflects on what he sees as the link between his autism and his creativity:

As I viewed the world with a different lens, a differing perspective, the influence on my creativity and making is not surprising. I don't think there has been a day where creativity hasn't been the major part of my life. As a child, I was always assembling, collecting and drawing – never letting go of those desires or a pencil ever since. At 6 years old, when asked what I wanted, I said 'to be an artist'. It seemed the most honest, logical and heartfelt answer I could give.

Jon Adams, 2016

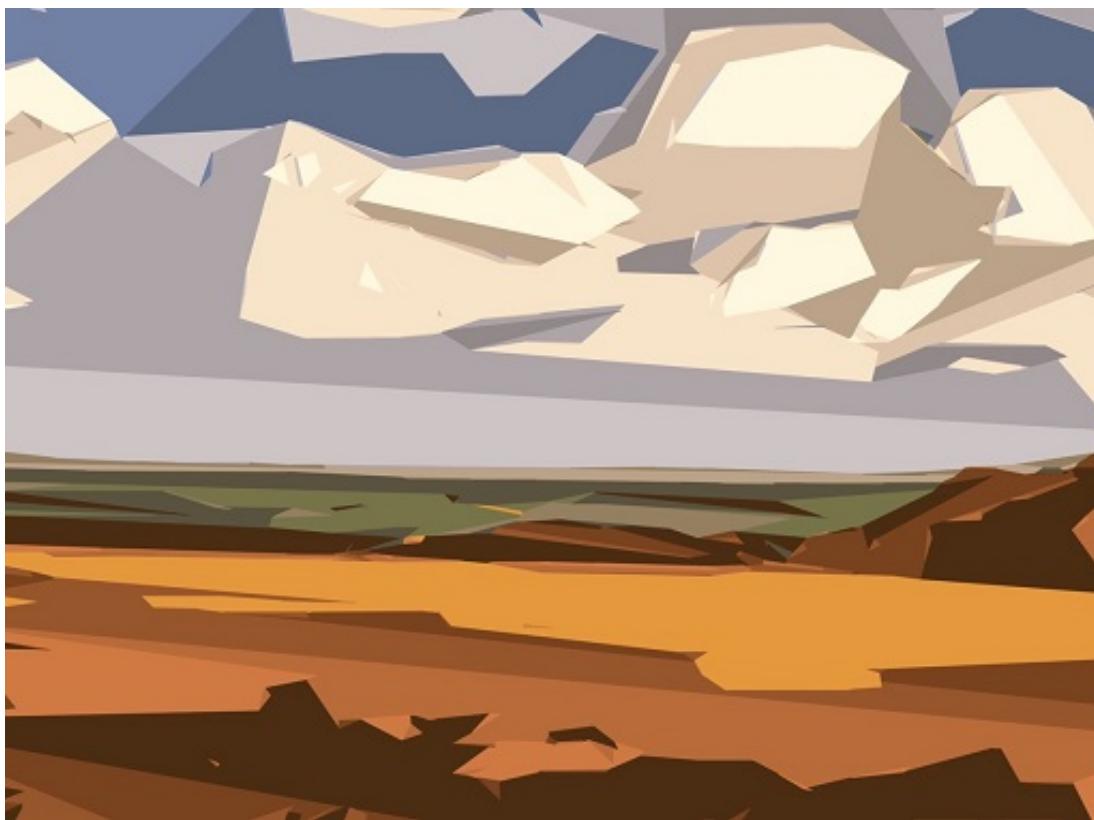


Figure 7 Landscape A by Jon Adams.

5.4 Managing exceptionality

The success and public interest enjoyed by exceptional autistic artists is as fulfilling and well-deserved as that of any gifted artist. Stephen Wiltshire has his own gallery in the Mall in London, where people can watch him creating his drawings and buy items from his extensive collection of works. Family members run the commercial side of his business.

Activity 3 Exceptional talent: positives and pitfalls

Allow about 10 minutes

In what ways do you think exceptional talent might benefit an autistic person and their family? What drawbacks might there be for the individual, and indeed for other autistic individuals and their families? Make a few notes.

Provide your answer...

Discussion

Working in a field that you enjoy and excel at is likely to be a source of well-being, self-esteem and income. Clearly, exceptionality must be managed so that the gifted autistic person is not exploited or treated as a spectacle.

Publicity for exceptional autistic talent could promote the idea that everyone on the autism spectrum has exceptional savant-type skills, such that autistic people without notable special skills and their parents may feel that everyone expects them to do

something exceptional. It is important to recognise and celebrate the exceptional individuals, but not to overlook the needs and difficulties of the majority with autism without extraordinary skills.

Arabella, Iris Grace's mother, discusses some of the pros and cons of her daughter's talent in the following clip:

Video content is not available in this format.

6 Further dimensions of autism

To conclude this week, two further sources of variation between autistic individuals will be considered.

6.1 Intellectual ability

Differences in **cognition**, that is, in thinking, learning and problem-solving skills are often represented in terms of **Intelligence Quotient (IQ)**. This is a standardised way of measuring intelligence using tests of both verbal and non-verbal ability. The IQ of people with autism ranges from scores of 70 and below, which corresponds to a profound intellectual disability, to 100, which is the average IQ for any population, to 130 and above, which corresponds to high or extremely high IQ.

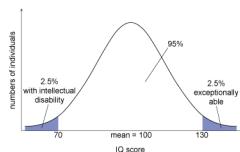


Figure 8 The characteristic bell-shaped distribution of IQ scores within the general population. Most people's IQ scores fall within the range 70 to 130. A minority of individuals have scores lower than 70 or higher than 130.

When a person has profound intellectual abilities, as defined by an IQ of less than 70, their autism has sometimes been described as '**low-functioning**'. This indicates that the person is profoundly affected, with overt speech and language problems, possibly being non-verbal even into adulthood. Autism in a person with an IQ of 70 or above has often been described as '**high-functioning**'. But this is misleading in several ways. Firstly, IQ scores in the range 70–99 are still below average; a person with an IQ of 85, for instance, may struggle with academic tasks. Secondly, 'high-functioning' might suggest that the person is not profoundly affected by their autistic symptoms. But social difficulties and repetitive behaviours can be profoundly disabling at any level of intellectual ability. For instance, an academically able autistic person may struggle to understand instructions or questions from teachers, especially if these are phrased in abstract language. They may find their learning environment stressful due to loud noise, bright lights and unusual smells, and they may expend considerable cognitive resources in 'pretending to be normal'. Consequently, even with a high IQ, a person's capacity to learn and thrive academically may be hampered by these additional factors. Alternatively, an academically successful person may find everyday tasks very challenging, as expressed here by Dr Wenn Lawson, writer, psychologist and autism advocate:

I have very uneven skills. This is another one of those enigmas. I have University degrees, I am married and I have three grown children. However, I have huge problems with being disorganised, getting lost, using public transport, understanding others, and just the practical interactions of social situations. I think many of you might be saying 'So what, I do as well.' I know that neural-typical individuals might have issues in these areas but I would suggest to you that it is the degree of the 'issue' that separates us. How many

of you need to sit down on the path outside of a supermarket and do breathing exercises because they have changed the tinned soup aisle?!

Lawson, 2018

6.2 Accompanying medical and psychological difficulties

In some individuals, autism goes together with other physical or psychological health problems. Perhaps the most common of these is epilepsy. It is estimated that up to one third of people on the autism spectrum may be prone to epilepsy, which is more common in 'low-functioning' autism (Viscidi et al., 2013). Some researchers believe that there are common sources for the atypical brain activity associated with autism and epilepsy. Fortunately there is a range of medications and treatment which can help to prevent seizures occurring, but sadly this is not always the case.

Other common problems that co-occur in some cases of autism are **dyslexia**, **Attention Deficit Hyperactivity Disorder (ADHD)** and **Obsessive Compulsive Disorder (OCD)**.

Here Alex talks about his obsession with handwashing, and how he overcame it.

Video content is not available in this format.

Depression and anxiety are also common in autistic people, and there may be many reasons for this. At school, young people with autism often experience bullying, because others perceive them as different or eccentric, and this may lead to low self-esteem and social isolation. Similarly at college, university or in the workplace, autistic people may find it hard to fit in and make friends, suffering all the more because they don't understand why.

Here Alex talks about his experiences of bullying at school.

Video content is not available in this format.

The NAS (National Autistic Society 2018a; 2018b) has further information about all the problems discussed in this section.

7 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 2 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

8 Summary

This week has provided an in-depth look at social and non-social characteristics of autism, and how they differ in their expression among autistic individuals. Some characteristics present difficulties or challenges for the individual and family members, while others are just unusual ways of engaging with the world and other people. Some traits, such as attention to detail, may be problematic in some situations, but highly beneficial in others. A minority of autistic people have exceptional talents, which may develop early and apparently without learning. Differences in IQ, and in the presence of accompanying problems like epilepsy, is another major source of variation across the spectrum.

You should now be able to:

- formulate a more detailed picture of autism characteristics and the challenges they may pose for the individual and their family
- have insights into autistic strengths, including special skills and outstanding talents
- appreciate ways in which the profile of difficulties and strengths varies between different individuals
- understand that the autism spectrum encompasses striking IQ differences between individuals
- recognise the presence of accompanying problems such as epilepsy or dyslexia in some cases.

Next week considers how the characteristics of autism are used within diagnosis

Now you can go to Week 3.

Week 3: Identifying and diagnosing autism

Introduction

This week starts with the earliest years of a child's life, when there may be subtle clues that a child is developing differently. Video clips illustrate what parents notice, and include some parents' reflections on getting their children diagnosed in the 1960s. The two main current diagnostic systems are introduced, followed by clips providing parental and personal experiences of diagnosis. The week ends with a look at two key challenges for diagnosis: different presentation of autism in females, and diagnosis in world cultures with differing expectations about typical behaviour.

Now watch the video in which Dr Ilona Roth introduces this week's work.

Video content is not available in this format.

By the end of this week you should be able to:

- describe behaviour in the first 2 years which may provide early indicators of autism
- appreciate the contributions made by parental accounts
- recognise internationally used diagnostic criteria and broad principles of diagnostic assessment
- appreciate different reactions to diagnosis
- understand challenges to diagnosis posed by gender and cross-cultural differences.

1 Early clues to autism

It is generally considered that autism cannot be reliably diagnosed before the age of 2 years. However, for some children later diagnosed with autism, parents report subtle differences from typical developmental milestones during the first year of life, such as delays in sitting up or walking (Chawarska et.al., 2007), or say that their child did not enjoy cuddles, or was difficult to feed or to comfort (Young, Brewer and Pattison, 2003).

1.1 Birth to 12 months

Where parents are recalling their child's first months, their memories may well be influenced by the child's subsequent diagnosis. They may reinterpret particular behaviours that did not cause concern at the time. For this reason, a family's home videos of their child's first months are invaluable for retrospective research, as direct observations of the child can be made. In one such study, researchers applied an observational method (see Week 1) to extracts from home videos loaned by parents, exploring whether infants later diagnosed with autism showed as much interest in people as a typically developing (TD) control group of children (Maestro and Muratori, 2008). Infants aged 0–6 months who were later diagnosed were less likely than TD children to look, smile or make sounds to people. From 6–12 months the infants later diagnosed became more likely to look, smile and talk to objects than to other people, and although they did also show increased reactions to people, this remained at a lower level than the TD infants.

1.2 12 to 24 months

It is often in the second year of life (12–24 months), when language, communication and play are beginning to take off in TD children, that important differences start to emerge, and are picked up by parents. They may notice difficulties with speech and language development, apparent indifference to others, dislike of change, or eating and sleeping issues. They may also notice that the child plays unusually, for instance repeatedly tipping bricks out of their container and then putting them back, rather than building with them. These possible signs may be particularly evident in children later diagnosed as 'lower-functioning'. The more subtle symptoms of 'high-functioning' autism may go unnoticed for much longer, especially if, rather than showing developmental delays, a child seems particularly precocious. For instance, some parents report that their child showed strikingly early skills in reading or naming things.

Between 12 to 24 months, children subsequently diagnosed with autism may show little response to what is said to them (known as difficulty with **receptive language**), and may not use their few words in a meaningful way (known as difficulty with **expressive language**). Often this will lead to a hearing check before autism is considered. Children may also exhibit **echolalia** – simply repeating what has been said to them instead of responding in a typical way. For instance if asked 'Do you want a drink?', a child may just repeat that rather than saying 'Yes please'. This may indicate a lack of **reciprocity**, the two-way use of language. Another example of poor reciprocity is difficulty taking turns in conversation, such that the person may seem to be in a monologue rather than a dialogue. Even if a child shows no delay or difficulty in developing grammar, vocabulary and other language features, this difficulty in turn-taking may be indicative.

Also in this second year, children subsequently diagnosed with autism may show little **eye contact** (looking directly at another person), or **joint attention**, whether looking towards something that another person is looking at, or engaging another person to look where they are looking. One way that TD children do this is by **protodeclarative pointing**, that is, pointing simply to indicate or share with others their interest in something. Another noticeable difference in an autistic toddler is absence of **pretend play**, such as 'driving a vehicle' consisting of a large cardboard box (Barbaro and Dissanayake, 2013).

1.3 Can typical development plateau out?

Some parents report that their baby seemed to be developing perfectly normally, until at some point (typically during the second year) this development seemed to 'plateau out' or even go backwards. In the past this pattern was thought to reflect a specific 'regressive' form of autism. Some experts no longer accept this view, arguing instead that most infants later diagnosed with autism undergo early subtle changes in the speed and direction of development, which may include the loss of previously acquired skills (Dobbs, 2017). These different views are still not reconciled.

1.4 Parents' reflections on their children's behaviour

In the following activity, video clips will show parents' observations of their children's behaviour.

Activity 1 What parents noticed

Allow about 20 minutes

Watch the following video clips from *The Autism Puzzle* (2003), in which parents and family members, some whose children were diagnosed in the 1960s, and others from recent years, talk about their children's behaviour in the first few years. List some key behavioural features mentioned for each child.

Michael Baron on his son Timothy

Video content is not available in this format.

Provide your answer...

Saskia Baron on Timothy

Video content is not available in this format.

Provide your answer...

Lorna Wing on her daughter Susan

Video content is not available in this format.

Provide your answer...

Hannelore Braunsberg on her son David

Video content is not available in this format.

Provide your answer...

Charlotte Moore on her son George

Video content is not available in this format.

Provide your answer...

Acis Peters and his mother Samantha

Video content is not available in this format.

Provide your answer...

Harry Peters and his mother Samantha

Video content is not available in this format.

Provide your answer...

Discussion

Key behaviours and problems noted by parents include:

Timothy Baron: initial pre-speech sounds disappeared; odd way of looking at mother.

Susan Wing: socially remote; did not look straight at people or pay attention to them; screamed, was 'difficult' and did not sleep; repetitive behaviours.

David Braunsberg: no communication; rejected solid foods; active and 'difficult'; still in nappies at 4.

George Moore: initially seemed bright, advanced and attentive to everything; was early to smile, speak, stand and walk; liked stories, had excellent memory for words and phrases; language use quaint or unusual; sleep problems.

Acis: language developed late; would not look at his Mum or point; appeared indifferent to sounds including others talking to him.

Harry: obsession with wearing the same pyjamas; wouldn't tolerate anything different.

As this activity shows, there are both similarities and differences in what parents notice. For some parents sleep problems, inflexibility or just 'difficult behaviour' stood out, while for others, it was differences in attention, looking or language. Two parents, Michael and Charlotte, thought that their child had regressed. Notice that despite his earlier language delay, 8 year old Acis is a very verbal child.

2 What is diagnosis?

As you have seen, some parents develop early and well-founded concerns about their infant's development. Specialist assessment is important, even if this serves to rule out autism. The fact that a child is, for instance, late in developing language, shy, or plays in an unusual way does not necessarily mean that the child has autism. By contrast, some parents may notice nothing unusual about their child's development until he or she goes to school, when teachers report that the child is troubled by the presence of other children, by the physical environment of the school, or in other ways. Parents in this situation may be surprised and shocked that autism is suggested as a possible basis for their child's difficulties. Some individuals are well into adulthood, feeling perhaps different from others, but not knowing why, before they are formally diagnosed. Finally, it is thought that many individuals in countries like the UK have undiagnosed autism, and in many **Lower and Middle Income Countries (LMIC)** around the world, this is sadly the rule rather than the exception. In all these different situations, formal diagnosis is the 'gold standard' for deciding whether or not an individual meets the criteria for an autism spectrum diagnosis, but is not always readily available.

2.1 The role of diagnosis

Early diagnosis is highly desirable, as early intervention has been shown to help improve social and communication skills. However, even at 24 months, when some parents can be fairly certain that their child is developing differently, healthcare professionals may not give parents' concerns the importance they deserve. And when referrals are made there is often, unfortunately, a long wait before assessment and diagnosis.

2.2 DSM-5, ICD-10 and ICD-11

Diagnosis, whether of a physical or psychological condition, involves comparing an individual's symptoms with **diagnostic criteria** which specify which symptoms must be present for a specific diagnosis to be appropriate, together with any criteria that rule out this particular diagnosis.

There are two main official sources for autism diagnosis, the **Diagnostic and Statistical Manual of Mental Disorders (DSM)** (published by the American Psychiatric Association), and the **International Classification of Diseases (ICD)** (published by the World Health Organisation). DSM is favoured in the USA while ICD is widely used in Europe, although the DSM criteria are also influential in Europe. Both systems are also used in many other parts of the world. However, the appropriateness of western-oriented criteria for diagnosis in different cultures is questionable, as will be discussed later on.

As you learned in Weeks 1 and 2, autism involves 'social' and 'non-social' characteristics. How these are used as the basis for diagnosis depends on which diagnostic system is used. ICD-10 (the tenth version of the ICD) was introduced in 1992 (WHO, 1992) and reflects thinking about the autism spectrum at that time, including some ideas that may be familiar, such as considering Asperger syndrome a separable sub-type of autism. DSM-5 (the fifth version of the manual) was introduced in 2013 and reflects more recent thinking, including the removal of Asperger syndrome as a separable sub-type. It is important to

understand the evolution from ICD-10 to DSM-5. At the time of finalising this module, both remain in operation. The details of ICD-11 were released in June 2018. After presentation to WHO member states in 2019, it will come into use in 2022. It will mirror DSM-5 in most key respects but includes some different features which are being viewed as improvements (Zeldovich, 2017). Table 1 summarises the key differences between ICD-10 and DSM-5, with some additional notes on ICD-11. For all autism diagnoses, an overarching criterion is whether the observed symptoms are sufficient to undermine the individual's functioning in everyday life. A clinician may decide, for instance, that a person's mild problems of social communication, and slightly repetitive behaviours and interests are not sufficiently disruptive to merit diagnosis.

Differences between ICD-10 and DSM-5, with explanatory notes

	ICD-10	DSM-5	Comments
What are the possible diagnoses?	Three different autism subtypes: Childhood autism; Asperger syndrome; Pervasive developmental disorder – unspecified (information insufficient to diagnose autism or Asperger syndrome).	A single diagnosis: Autism spectrum disorder.	In ICD-10, the 'spectrum' is divided into three subtypes. DSM-5 has relinquished subtypes such as Asperger in favour of a single continuous spectrum, reflecting the variability of symptoms and how they are expressed. ICD-11 mirrors this DSM-5 approach, but does differentiate autism with and without intellectual disability.
What are the main types of symptom?	Three: Problems in: 1) communication 2) social interaction 3) restrictive, repetitive activities and interests (RRBIs).	Two: Problems in: 1) social communication 2) restrictive, repetitive activities and interests; sensory difficulties.	DSM-5 and ICD-11 both merge communication and social interaction into one social communication symptom cluster. Clinicians had found it hard to categorise symptoms as either, as the difficulties are interrelated. For instance, if a child has limited language (a communication problem) this will almost inevitably limit social interaction.
By what age must symptoms have appeared for diagnostic criteria to be met?	For childhood autism (but not for Asperger syndrome) 'functional impairment' in social interaction, or in language use for communication, must	Social communication difficulties and RRBIs must have been present in early childhood; however, 'functional impairment' need not be apparent till later.	DSM-5 criteria accommodate cases where early childhood symptoms only become apparent later than 3 years of age. This allows for what was formerly Asperger

	have appeared by age 3 years.		syndrome within a continuum of different developmental profiles.
Sensory problems are common in autism: how are these represented in the criteria?	The ICD-10 criteria do not include sensory problems as a formal criterion.	DSM-5 includes sensory hyper/hyposensitivities as part of the 'non-social' RRBI cluster of symptoms.	The evidence that sensory difficulties occur in a majority of autistic people, convinced the DSM-5 working groups to include them as a diagnostic criterion. ICD-11 has done the same.
How are differences in symptoms and severity represented in diagnosis?	Mainly through use of the three sub-diagnoses.	Evaluation of severity (level 1, 2 and 3) is an integral part of the diagnosis.	The DSM-5 severity scores should help clinicians to avoid the confusing informal terms 'high-functioning' and 'low-functioning'.
How are additional problems beyond the main symptom clusters represented?	In ICD-10, problems such as epilepsy or dyslexia would be noted as clinical features beyond the main diagnosis.	In DSM-5, problems such as epilepsy, dyslexia or intellectual disability are combined with the individual's diagnosis as 'specifiers' – additional problems which help to characterise the individual's case.	The aim of the DSM-5 specifiers is to make each diagnosis as precise and specific as possible to the individual person. ICD-11 adopts similar principles, but treats autism with and without intellectual disability as distinct sub-diagnoses.

Activity 2 Additional symptoms with significance

Allow about 5 minutes

From the feedback to [Activity 1](#), can you identify one or more behaviours highlighted by parents but not included within the ICD-10 or DSM-5 core diagnostic criteria?

Provide your answer...

Answer

Several parents report their children's sleep problems. Charlotte, George's mother, mentions his precocious motor development and exceptional memory for words and phrases.

2.3 How is diagnosis carried out?

Diagnostic practice depends on the professionals involved, how they work, geographical area and country. In the UK, a school educational psychologist, GP or paediatrician may be involved in the early stages; a clinical psychologist or psychiatrist may make the diagnosis alone, but diagnosis will typically involve different specialists working as a team. An individual's journey to diagnosis can involve problems, delays, distress and conflicting information. In the UK, most local authorities have defined procedures or 'pathways', that specify the process by which children suspected of having a special educational need are referred for specialist assessment and/or diagnostic evaluation. The **National Autism Plan for Children (NAPC)** is a UK framework containing guidelines and recommendations for good practice in relation to the identification and diagnosis of children with autism (NIASA, 2003). Pathways for adult diagnosis are less well-developed but the Autism Act (2009) has required all local authorities to develop them.

The process of assessing a child or adult usually involves a **diagnostic instrument** or tool, designed to ensure consistent application of the diagnostic criteria themselves. One is the **Autism Diagnostic Observation Schedule (ADOS)**, comprising 'modules' for assessing children of different age groups. A trained practitioner selects the appropriate module (e.g. toys and games for age 2) and uses it to assess whether the individual has 'age appropriate skills and behaviour' – for instance, for a 2 year old, these will involve play, joint attention and language. The **Autism Diagnostic Interview - Revised (ADI-R)** comprises questions for parents about their child's current skills and past behaviour. Alternative instruments include the **Diagnostic Interview for Social and Communication Disorders (DISCO)**, and the Developmental, Dimensional and Diagnostic Interview (3di). Multiple tools may be used in an assessment.



Figure 1 Equipment used in the ADOS.

Activity 3 A diagnostic tool in action

Allow about 10 minutes

The following two clips feature expert Dr Amitta Shah using the DISCO in a diagnostic session with a young boy and his parents. Attending the session and providing commentary is clinical psychologist, Dr Laverne Antrobus. The interview itself focuses on the parents' recall of their child's early behaviour and their current concerns. As you watch the clips, note three other sources of evidence that Dr Shah says she has used in making the diagnosis.

Video content is not available in this format.

Video content is not available in this format.

Provide your answer...

Discussion

Dr Shah mentions reports from the paediatrician, DVDs and also meeting the child himself, which has enabled her to observe him directly. This integration of different evidence sources is typical of diagnostic tools for autism and is a key feature of the DISCO.

3 Experiences of diagnosis

Families and individuals vary in how they react to an autism spectrum diagnosis. Sometimes it comes as a relief, with parents having an explanation for the differences they see in their children, and which others may comment on. Other reactions may include grief, surprise, devastation, disbelief, anger, guilt or helplessness, sometimes together with depression. While parents may come to terms with the diagnosis, other family members may find it very difficult. For people diagnosed in adulthood, diagnosis often helps to explain years of struggling with a feeling of difference.

The following clips illustrate the reactions of parents and individuals over the years.

3.1 The first diagnoses

Back in the 1960s, parents of some of the first UK children to be diagnosed had to contend with the view that the autism was 'their fault'. In the pioneering group of parents featured here, this stigmatising perception engendered disbelief and a determination to challenge the prevailing attitudes.

Timothy Baron was one of the first children to be diagnosed in the UK. His difficulties became apparent quite early – at 15 months – when his initial babbling began to disappear. However, his parents ignored advice to put him in an institution. Michael, his father, was one of the pioneering group who established the National Autistic Society, and its founding chair. Here first is Timothy's sister, filmmaker Saskia Baron:

Video content is not available in this format.

Video content is not available in this format.

Note that the paediatrician who diagnosed Timothy had apparently picked up new information about autism while in the States. The diagnosis given was 'childhood psychosis'. The term autism did not yet appear in diagnostic classifications, and clinicians often used 'childhood psychosis' and 'childhood schizophrenia' interchangeably with it – though it was later demonstrated that autism had distinct symptoms. Nowadays many more professionals have knowledge of autism, and diagnosis is more likely to be carried out by a multidisciplinary team.

3.2 Parental blame: fighting back

Here are two more pioneering parents: Lorna Wing, who became a leading autism expert, followed by Hannelore Braunsberg. These days, Hannelore's son David, who appears in the clip, is a talented artist. Both these parents contested the stigmatising explanation for their children's condition.

Video content is not available in this format.

3.3 Experiences of diagnosis: 1990s to now

Despite huge progress in diagnostic practices since the 1960s, parents' reactions still vary widely, depending on what they were expecting, and also how the diagnoses were given. In these clips, note the efforts of all three parents to find positives in their child's diagnosis. Charlotte Moore had been relieved to have an explanation of why her son George, born in 1990, was still in nappies at age 4. Her second son, Sam, born in 1992, was also diagnosed with autism.

Video content is not available in this format.

Mark and his wife had imagined that Zack's problem was primarily a failure to develop speech, and had to come to terms with the diagnosis of a lifelong developmental condition. Mark talks of profound shock, and emotions similar to bereavement and mourning. Yet he describes with warmth the realisation that Zack was just the same person as before the diagnosis, and of the progress they have both helped Zack to make.

Video content is not available in this format.

Arabella was not comfortable with the way diagnosis of her daughter Iris Grace, born in 2009, was delivered. She stresses the need for parents to receive positive messages and a sense of empowerment.

Video content is not available in this format.

3.4 Experiencing diagnosis in adulthood

Nowadays it is not uncommon for an adult to receive a diagnosis after a younger family member has been diagnosed. John Peters was born in the 1940s. He is articulate and sociable, with an obsessive interest in collecting and hoarding objects. He was diagnosed with Asperger syndrome around two decades ago, after specialists assessing his two grandchildren, Acis and Harry, noticed his unusual behaviour. His Asperger syndrome diagnosis implies that he showed no delay in language development as an infant. John's teenage behaviour was probably seen as eccentric, but in the period when he was growing up, a profile of skills and behaviour like his did not match the symptoms of autism as then described, and Asperger syndrome was not recognised.

Activity 4 On being diagnosed as an adult

Allow about 10 minutes

Watch these clips about John Peters. Note one positive and one negative feeling that John experienced on being diagnosed.

Video content is not available in this format.

Video content is not available in this format.

Video content is not available in this format.

Positive:

-
- Negative:
-

Discussion

John's diagnosis has helped him to explain feeling different, and other problems that he has suffered with all his life. However, he also refers to a deep sense of guilt. This may be partly because he now realises that he was difficult to live with, and also because he has passed 'autism genes' to his grandchildren. He feels that if his own diagnosis had been known, Acis and Harry's difficulties would have been explained earlier.

3.5 After diagnosis

Diagnosis is merely the beginning of a long journey. For parents, it can mean struggling to access appropriate education (both pre-school and school) and worthwhile interventions. You will read more about these in later weeks. Families are usually keen to know the **prognosis**, that is, the likely outcome in the longer term. This however is very difficult to predict. Some individuals may need a high level of care and support all their lives, some may need a moderate amount of help with daily living skills and may be able to work part-time, whereas others are able to live independently, hold down a full-time job and get married.

Activity 5 The benefits and drawbacks of diagnosis

Allow about 15 minutes

You have seen that coming to terms with diagnosis is a challenge for any family. Some parents who are aware their child has difficulties may even avoid formal diagnosis, fearing that the 'autism' label will be detrimental.

Reflecting on what you have read and the video clips you have viewed, note three positive consequences of diagnosis and one potentially negative consequence.

Positive:

-
-
-

Negative:

-
-
-

Answer

Positives

Diagnosis:

- helps parents to understand behavioural differences that have concerned them
- explains why a person is very good at some things and struggles with others
- may help other people to accept why a child or adult behaves unusually
- may, particularly for a child, enable access to services and interventions, as well as appropriate support at school and/or social care services
- may, particularly for an adult, provide self-understanding, enabling the person to accept 'who they are'.

Negatives

Diagnosis may:

- be hard for some family members to accept, leading to rifts
- serve as a stigmatising label
- cause uncomfortable emotions such as guilt.

Now watch this clip in which Arabella concludes in favour of diagnosis, despite the ups and downs:

Video content is not available in this format.

4 Challenges for diagnosis

The prevalence of autism, an estimate of the number of individuals in a population identified as matching the autism diagnosis, is currently quoted as just over 1 in 100 children UK-wide (NAS, n.d.). But this figure is not consistent across all UK subgroups of people, let alone across different countries of the world. Here we consider two reasons for these differences.

4.1 Autism in females

Prevalence estimates for autism in males are consistently much higher than for autism in females, suggesting that four times as many males are diagnosed as females. This male/female disparity may even be as high as 10:1 if considering only males and females with high-functioning autism. There is much ongoing research into genetic and other biological factors which might make boys more susceptible to autism than girls. But there is also increasing evidence that autism diagnoses in girls are being missed.

Experts believe that autism characteristics in girls and women do not necessarily match the stereotype of obsessive interest in machines and other physical systems, coupled with obvious social withdrawal. Girls on the autism spectrum may have more ‘typically female’ interests, such as fashion or fiction, such that an unusually obsessive focus on the interest, or an unusual way of engaging with it, goes unnoticed by parents and peers, especially in intellectually able girls. Through an interest in other people’s behaviour, and/or a strong desire to conform, girls may strive hard to appear sociable, emulating the behaviour of their peers. This is well illustrated in this extract from Liane Holliday Willey’s autobiography:

My mother tells me I was very good at capturing the essence and persona of people. At times I literally copied someone’s looks and their actions. I was uncanny in my ability to copy accents, vocal inflections, facial expressions, hand movements, gaits and tiny gestures. It was as if I became the person I was emulating.

(Willey, 1999, p. 22)

Girls may work hard to camouflage their autism, struggling for years with an underlying sense of isolation and difference. Even where parents express concerns to professionals, for instance because their daughter is extremely ‘faddish’ about food, autism may be dismissed because other areas of the child’s behaviour ‘don’t fit’. An increasing number of females are receiving diagnosis in adulthood, sometimes after treatment for an accompanying condition such as depression or anorexia. Experts are considering whether diagnostic tools need adjustment to be more ‘gender neutral’. Nonetheless, underdiagnosis alone is unlikely to explain all of the marked excess of males over females on the autism spectrum, suggesting that there is also increased biological risk in males.

See Lai et al. (2015) for a review of the evidence and ideas covered in this section.

4.2 Diagnosing autism in different cultures

In many developing countries, access to diagnosis is extremely limited, which contributes to strikingly lower prevalence estimates (Elsabbagh et al., 2012). There is also evidence for variations in diagnosis rates between different ethnic communities within a given country (Begeer et al., 2009).

Most diagnostic criteria and tools have been developed in the UK and US and reflect the majority Western understanding of what is typical behaviour and what constitutes significant difference. Beyond the challenge of making diagnosis available wherever it is needed, there is the issue of what diagnostic criteria and instruments are appropriate to use; cultural norms for behaviour must be considered (Norbury and Sparks, 2013).

Activity 6 What factors affect varying prevalence estimates across cultures?

Allow about 10 minutes

In these clips, Dr Prithvi Perepa, of Northampton University, draws on his own research to consider the implications of cross-cultural factors for diagnosis of autism. As you watch the clips, note the main factors he mentions.

Clips 1 and 2

Video content is not available in this format.

Video content is not available in this format.

Provide your answer...

Discussion

Prithvi acknowledges that limited access to diagnostic services will have an impact on prevalence estimates: fewer diagnosed cases means lower prevalence. However, he also stresses that culturally different understandings of autism, may affect whether particular behavioural traits are seen as atypical or not.

Clip 3

Video content is not available in this format.

Provide your answer...

Discussion

Culturally different expectations may be particularly marked concerning children's early developmental milestones. For example, whereas imaginative pretend play is considered an important milestone in the West, some cultures prefer their children's play to be 'functional' e.g. the ability to stack toy bricks would be considered more important than using them as 'cups' for pretending to drink. In certain African cultures,

children are not expected to refer to themselves with personal pronouns such as 'I', and in India, boys are not expected to develop speech early. Such differences are likely to affect whether and when a parent forms concerns about their child's development.

Clip 4

Besides differences in cultural expectations for developmental milestones, there may be differences concerning acceptable social behaviour. Such cultural differences may exist in UK-based ethnic minorities, as well as across different world cultures, as Dr Perepa explains.

Video content is not available in this format.

Provide your answer...

Discussion

Besides different expectations for development, acceptable social behaviour may differ. For instance, in some countries, it is considered disrespectful for a child to engage in eye contact with an adult. So lack of eye contact would not give a parent cause for concern. Such cultural differences may exist in UK-based ethnic minorities, as well as across different world cultures

4.3 The effects of stigma

Even when parents are aware that their child has a problem, shame or fear of societal stigma may deter them from seeking appropriate help. For instance, in South Korean culture, some consider autism to be a 'genetic taint', which diminishes the marriage prospects of other children in the family. Parents may be reluctant to come forward, or may seek a diagnosis of 'Reactive attachment disorder', which implicates the mother's behaviour in causing the child's difficulties (Grinker et al., 2011).

Yet, as Dr Perepa explains, the role of stigma in explaining different rates of diagnosis across ethnic groups is complex and requires more research.

Video content is not available in this format.

We will return to the global perspective in Week 8.

5 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 3 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

6 Summary

This week has considered clues to autism in early childhood, highlighting subtle differences from typical development which parents tend to notice. After introducing the diagnostic criteria and diagnostic process, the focus moved to parents' and individuals' experiences of diagnosis, considering both the positives and the negatives. Finally, the week considered the likelihood that girls are being underdiagnosed because their behaviour does not match autism stereotypes, and the challenges of diagnosis in cross-cultural settings.

You should now be able to:

- describe behaviour in the first 2 years which may provide early indicators of autism
- appreciate the contributions made by parental accounts
- recognise internationally used diagnostic criteria and broad principles of diagnostic assessment
- appreciate different reactions to diagnosis
- understand challenges to diagnosis posed by gender and cross-cultural differences.

Next week you will look at psychological and biological explanations for autism.

Now you can go to Week 4.

Week 4: Explaining autism: mind and brain

Introduction

In Weeks 1 to 3, you gained a picture of how the behaviour and thinking style of autistic people may differ from that of neurotypical people, and you have learned which of these key differences form the basis for diagnosis. But how and why do such differences come about? This is a question that scientists have tried to answer, offering explanations or **theories** about the **psychology** of autism (how the mind works), the **neurobiology** (structure and function of the brain and nervous system), and genetics (the influence of **genes** in a person's physical and psychological traits, in this case making autism more likely to occur in some people than others). This week we will consider selected highlights of this scientific work. Notice that some of these studies consider relationships between different levels (psychology, neurobiology and genetics).

Now watch the following video in which Dr Ilona Roth introduces this week's work.

Video content is not available in this format.

By the end of this week you should be able to:

- understand key approaches to explaining autism
- differentiate three levels of explanation: psychological, neurobiological and genetic
- understand key psychological accounts of the autistic 'thinking style' and identify implications for everyday life
- appreciate key ideas about brain and nervous system function in autism
- appreciate the complex role of genetic influences in autism.

1 The psychology of autism: explaining social characteristics

Psychological theories of autism seek to explain the characteristic behaviour and thinking style in terms of underlying **psychological processes**, that is, how autistic people process information about other people and the environment. Some theories have a primary focus on either the social traits or the non-social traits, so these theories are not

mutually exclusive. Further theories have tried to bring the social and non-social areas of difference together within a single framework.

We will start with the theory known, confusingly, as ‘Theory of Mind’ theory, which is probably the most influential explanation of the social challenges in autism.

1.1 Theory of Mind

Back in the 1980s, autism researchers Simon Baron-Cohen, Uta Frith and Alan Leslie set out to investigate why children and adults with autism seemed prone to misunderstanding social situations, and were claimed to be unaware of other people’s feelings. They devised an elegant psychological test which suggested that most children with autism have great difficulty in ‘putting themselves in another person’s shoes’, that is, understanding that others have thoughts, knowledge, beliefs, desires and goals which may differ from their own. This difficulty in understanding other people’s thoughts and points of view is known as a **Theory of Mind (ToM)** or ‘mindreading’ problem (Baron-Cohen, Leslie and Frith, 1983).

1.2 False belief

The task, developed by Baron-Cohen and his colleagues and used frequently in subsequent studies, is known as the **Sally–Anne false belief task**. Before watching the animation illustrating the task (Activity 1), consider the following imaginary scenario, an everyday example of the kind of skill that Baron-Cohen was exploring.

You and a friend, Kelly, drive to the shops in your car. You park in a particular street (Mount Street) and as you both have different shops to visit, you arrange to meet back at the car in an hour’s time. Shortly after parting from your friend, you realise that you have left your wallet at home, so you drive home to fetch it. When you get back to where you parked before, the parking spaces are full, so you have to park in a different street (Park Street). You know that when Kelly goes to meet you she *will have the false belief* that the car is where you originally parked it. Unless you can contact her first, she will go to meet you in Mount Street, not in Park Street.

Of course these days, mobile phones offer a ready solution to problems like this. The point is to illustrate what neurotypical people routinely understand or figure out about what another person is thinking. Without an understanding that Kelly would hold a false belief about your meeting place, you would not even realise that it was necessary to redirect her! So the ability to understand false belief is an important aspect of understanding other people’s thoughts and beliefs – that is, theory of mind.

1.3 The Sally–Anne false belief task

Activity 1 Try out the Sally–Anne false belief task

Allow about 10 minutes

Simon Baron-Cohen used the Sally–Anne task to investigate whether autistic children could understand false belief. The following download contains an animation that

illustrates this test and his results. After watching the animation, answer the three questions that follow it, and pay careful attention to the feedback.

You can find the [downloadable Sally-Anne task at this link](#).

You can find [instructions for downloading and using the Sally-Anne task at this link](#).

If you can't use this download, or prefer not to, here is an image showing the key contents of the animation:



Figure 1 The Sally-Anne false belief task.

When this task is used with typically developing children, it is found that over the age of 4–5 years, most are able to correctly identify that Sally has a false belief about the location of the marble.

Activity 2 Children taking the Sally–Anne task

Allow about 10 minutes

Now watch a short video, in which Baron-Cohen first tested two children with autism and then a younger neurotypical child on the task. Notice that most children with autism (around 80%) fail on the 'belief' question 'Where will Sally look for her marble?', while children in the two control groups mostly pass. What does failure on the belief question suggest? Note down your explanation.

Video content is not available in this format.

Provide your answer...

Discussion

Baron-Cohen and his colleagues argued that instead of 'putting themselves in Sally's shoes', the autistic children assume that Sally's belief about where she will find her marble is the same as their own knowledge of where the marble really is. In short, the study suggests that children with autism have difficulty understanding another person's thoughts, which in this case are different from their own.

The basic finding of the Sally–Anne task has been **replicated** (repeated with the same outcome) many times, with numerous variants of the task. However, the number of autistic children failing the Sally–Anne task does vary from one study to another.

Note that the task does not offer a way of diagnosing autism. Not all autistic people fail it, and some neurotypical people may also find it difficult.

Over the decades since the Sally-Anne false belief task findings were first reported, their implications have been widely questioned and qualified. However, a quite common occurrence in autism is that a person fails to give some crucial information to another person. This could well reflect a problem in understanding other people's knowledge of a situation.

Activity 3 A real-life ToM problem?

Allow about 5 minutes

Read the following extract, and explain how it fits with the idea that ToM is a challenge for autistic people:

One of the most recurrent problems throughout middle childhood was my constant failure to distinguish between my knowledge and that of others. Very often my parents would miss deadlines or appointments because I failed to tell them of these matters. For instance, my parents missed the school's Open House in my fifth grade and my mom asked me afterward 'why didn't you tell us about it?' 'I thought you knew it', I replied.

Sarah quoted in Sainsbury, 2000, p. 60

Provide your answer...

Discussion

Sarah seems not to understand that her parents don't have exactly the same thoughts as she does. Because she has not told them about the Open House at school, they have no knowledge that it is due to happen.

1.4 Theory of Mind and thinking literally

ToM is about understanding other people's **mental states**, that is their beliefs, intentions, feelings and so on. Some researchers have suggested a link between ToM difficulties and 'literal-mindedness' in autism. As you learned in Week 2, in everyday situations, people often say one thing while actually meaning or intending something else. For instance, when people speak ironically or sarcastically, understanding what they really mean depends on 'reading behind' what they say to their intentions given the context. To test how autistic people interpret non-literal utterances, Francesca Happé devised the 'Strange stories' test (Happé, 1994).

Participants in the test were presented with stories like this one which contains an example of irony:

Ann's mother has spent a long time cooking Ann's favourite meal: fish and chips. But when she brings it in, Ann is watching TV, and she doesn't even look up or say thank you. Ann's mother is cross and says 'Well that's very nice isn't it! That's what I call politeness!'

The participants were asked:

Question 1: Is it true what Ann's mother says?

Question 2: Why does Ann's mother say this?



Figure 2 Ann and her mother.

While autistic participants were able to identify that what Ann's mother says is not true, most struggle to identify why she might say it, suggesting, for instance, that she was 'having a joke'. A person who has difficulty in reading the meanings and intentions behind other people's utterances may find all such expressions, interpreted literally, really puzzling or disconcerting. The consequences can sometimes be really profound.

In this extract, Wenn Lawson describes how, years ago when autism was less well known, his literal interpretation of questions from a psychiatrist led him to be misdiagnosed with schizophrenia (Lawson and Roth, 2011).

Audio content is not available in this format.

In Week 2 you viewed two video clips titled 'Socially awkward' and 'Misunderstanding', which you might like to watch again, considering how ToM difficulties could affect the behaviour of the young man in the clip.

Just how ToM and language skills are linked is debatable (de Villiers, 2000). Autistic people with pronounced language problems are more likely to fail false belief tasks, possibly suggesting that language difficulties cause ToM difficulties rather than the other way round. With much greater awareness of literal-mindedness these days, organisations like the National Autistic Society advocate clear, straightforward language for communicating with people in the autistic community.

2 Psychology of autism: explaining non-social characteristics

You will recall from Week 2 that ‘non-social’ features of autism include the tendency to repeat particular movements or activities, to be stuck with familiar routines and to be resistant to anything new or unfamiliar, however insignificant the change might seem to others. Here we look at two theories which focus on these traits.

2.1 Executive function

Some experimental tests suggest that the profile just described reflects problems with **executive function** (Demetriou et al., 2017). This means the mental capacity to organise thoughts and actions to meet goals, for instance completing a task, shifting flexibly from one task to another, or thinking up new ideas for things to do. Executive function difficulties are not unique to autism – for instance, they occur in ADHD. One test of executive function in which children and adults with autism may have difficulty is the **Tower of Hanoi** puzzle, illustrated below.

Tower of Hanoi

The puzzle consists of three pegs, A, B and C, and a set of rings that vary in size. At the start of the test, the rings are arranged in order of size on peg A (see Figure 2). The aim is to move all the rings, one at a time and in as few moves as possible, to peg C, with the constraint that a larger ring can never be placed on top of a smaller ring. To succeed at this task the participant must work out an overall strategy or plan for transferring the rings – the secret is in the way all three pegs, including peg B, are used as ‘staging posts’.

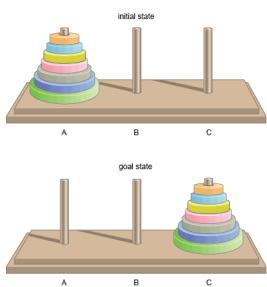


Figure 3 The Tower of Hanoi puzzle.

You might like to find an online version of the Tower of Hanoi puzzle (such as [this one](#)) and try it for yourself. (Note: neurotypical people as well as autistic people may find this task difficult. No conclusions can be drawn from finding the task challenging.)

Other executive function tasks test flexibility and the ability to generate new ideas.

Watch this video clip, in which Dr Jamie Craig asks first a child with autism, and then a typically developing child to suggest new uses for a piece of foam. You will notice that

while both children come up with some ideas, the typically developing child offers a greater and richer range of suggestions (Craig and Baron-Cohen, 1999).

Video content is not available in this format.

Executive function difficulties may be one reason why even able autistic people can find everyday life challenging. Difficulties with everyday organisational tasks are well illustrated in this interview extract with Wenn Lawson (Lawson and Roth, 2011):

Audio content is not available in this format.

2.2 Attention to detail

As you saw in Week 2, people on the autism spectrum often have a very good eye for detail, coupled with difficulty in 'seeing the wood for the trees', that is, in grasping the most salient aspects of a concept or idea. This thinking style is sometimes known as **weak central coherence**. Attention to visual detail has been studied with the **embedded figures test**, where the task is to find a simple shape such as a triangle, embedded in a larger figure. Some people on the autism spectrum find the embedded shape more easily and quickly than neurotypical people, suggesting that they are focusing on the details, not on the overall shape and identity of the figure (Happé and Booth, 2008).



Figure 4 Example of the embedded figures test. Can you pick out a shape within the pram figure that exactly matches the separate triangle?

This kind of visual eye for detail could be very useful in jobs such as quality control on a production line, where picking up subtle flaws in a product is crucial. Conversely, an autistic person may find it hard to work out what a whole object is from drawings of parts, or be unable to arrange apparently random sentences into a coherent story. This could, for instance, put a student at a disadvantage when trying to assemble information for an essay.

Weak central coherence could help to explain the narrow, specific focus of special interests and adherence to familiar routines in people with autism. Although changes to routines may seem minor and unimportant to a neurotypical person, for an autistic person, the feeling that everything is not exactly how they expect it and prefer it to be may provoke extreme anxiety.

Watch these video clips in which two autistic people describe their perfectionist tendencies.

Video content is not available in this format.

Video content is not available in this format.

Attention to detail by autistic people does not invariably show up in experimental tests. However, the theory does resonate with what a lot of autistic people experience, and also seeks to address strengths as well as challenges in the autistic thinking style. Next we will consider one more recent theory which aims to integrate some features of the approaches discussed so far.

3 Psychology of autism: an integrative explanation?

As you have seen, the ToM approach primarily focuses on social challenges in autism, while executive function and weak central coherence focus primarily on non-social aspects. In the early 2000s, Baron-Cohen proposed a new theory which combined revised ideas about the social difficulties with a new approach to the non-social differences. This is known as the **empathising–systemising theory**.

3.1 Recognising emotions

One stimulus for Baron-Cohen's new approach was some research suggesting that autistic people may struggle to understand other people's emotions or feelings. In one experimental test known as 'Reading the Mind in the Eyes', participants looked at images such as the one below, and had to choose which of the emotions mentioned was being portrayed (Baron-Cohen et al., 2001). Autistic adults had more difficulty than control participants, and often made the wrong choice.



Figure 5 Image from the 'Reading the Mind in the Eyes' test.

3.2 Empathising and systemising

Bringing earlier ToM work together with research on emotion recognition, Baron-Cohen proposed that autistic people may have difficulty with **empathising** – recognising or understanding other people's emotions, and reacting appropriately, leading to their difficulties in interacting with other people, making friends, and so on. At the same time, they may be strongly drawn to subject matter governed by systems or rules, leading to an interest in fields like physics, mathematics and technology, and in fact any domain which can be approached in a systematic rule-like way, which Baron-Cohen termed **systemising** (Baron-Cohen, 2009).

This quote from Luke Jackson, who wrote his own guide to Asperger syndrome when a teenager, illustrates a systemising approach in his fascination with chain reactions and springs.

I like the idea of chain reactions – one thing happening which triggers off another, which triggers off another and so on and so on. I used to put string round a dozen objects and watch them all fall down at once. That's why I love slinkies (coiled springs) so much. When you wind one round loads of things and then let go, it pulls itself through all of them.

Jackson 2002, p. 52

To provide evidence for the 'low empathising/high systemising profile', Baron-Cohen devised questionnaires – the **empathy quotient (EQ)** and the **systemising quotient (SQ)**. People were asked to evaluate how strongly they agreed or disagreed with statements such as 'I find it easy to put myself in someone else's shoes'.

Activity 4 Empathy Quotient and Systemising Quotient

Allow about 5 minutes

Here are some items from updated versions of the EQ and SQ. How do you think a person who was low on empathising and high on systemising might answer each of these questions? Choose 'Strongly agree' or 'Strongly disagree' for each.

Empathy quotient

1. I can't always see why someone should have felt offended by a remark
 - Strongly agree
 - Strongly disagree
2. I can pick up quickly if someone says one thing but means another
 - Strongly agree
 - Strongly disagree

Systemising quotient

3. I am fascinated by how machines work
 - Strongly agree
 - Strongly disagree
4. I rarely read articles or web pages about new technology
 - Strongly agree

- Strongly disagree

These items are from the Empathy Quotient (EQ) and Systemising Quotient (SQ) for Adults (Autism Research Centre, 2018)

From people's total questionnaire scores, Baron-Cohen reported that autistic respondents tended to score high on systemising and low on empathising, whereas few of the typically developed respondents tested showed the same pattern (Baron-Cohen et al., 2014).

According to this profile, autistic people have particular interests and skills in 'systematic' subjects such as engineering, science and computing, and are less interested or skilled in dealing with people and social relationships. This profile does seem broadly consistent with the diagnostic criteria, and the theory has the merit of attempting to integrate social and non-social characteristics. However, the approach has been strongly questioned (Subbaraman, 2014). Firstly, since the questionnaires are 'self-report', participants may choose their answers to fit a certain self-image, rather than their true preferences.

Secondly, the overall score differences between autistic and control groups of participants are small. Thirdly, the theory plays to a predominantly male stereotype of the autistic person as socially insensitive and obsessed with machines. But as you saw in Week 2, autistic people may have skills in many areas besides engineering, science and computing. They cannot be assumed to conform neatly to the empathising–systemising profile, and the way autism is expressed in women may be particularly far from this account.

3.3 What do psychological theories tell us?

Each of the psychological theories outlined this week is based on research, and offers possible insights into the thinking processes and experiences of individuals with autism. A serious limitation to all the theories is that the experimental evidence tends to come from 'high-functioning' individuals, who are able to understand and comply with task instructions. Even within this group, there are individual differences in the pattern of responses, highlighting once again the heterogeneity of autism. Also, autistic females are often under-represented in psychological tests, and when they are tested, there are some differences in how they respond (Mandy et al., 2012).

None of the approaches considered offers insights into unusual sensory responses, such as hyper- and hyposensitivity to sounds and other sensory stimuli. These affect a majority of people on the spectrum, but in different ways, which makes it hard for researchers to identify common underlying factors. Some recent research in this field focuses on differentiating the sensory issues in autism into different profiles, as a first step towards explaining underlying causes (Tomchek et al., 2018).

Psychological theories and tasks do provide a useful reference point for research into how underlying neurobiological differences relate to the behavioural characteristics of autism. We turn to neurobiology next.

4 The neurobiology of autism

Neurobiological research covers a range of levels from the structure and function of brain areas, to the way nerve cells communicate with one another, to the role of ‘chemical messengers’ such as hormones.

4.1 Brain structure and function

Research into the structure and function of the brain draws extensively on a range of **brain imaging** techniques. Magnetic Resonance Imaging (MRI) suggests that key brain structures may have a slightly different size or shape in autistic people. For instance, studies suggest that the brains of some young autistic children are 5–10% bigger than those of typically developing children, although this difference disappears by adolescence. Another area where increased size has been observed is the **amygdala**, a brain region involved in evaluating the emotional significance of external events. Overgrowth of the amygdala in children with autism is related to the severity of their social and communication difficulties, – greater overgrowth tends to go with more severe difficulties – but again this disparity of size compared with typical development disappears in adolescence.

Functional Magnetic Resonance Imaging (fMRI) monitors brain activity while a person is performing psychological tests, such as recognising faces, responding to emotional stimuli or understanding language.



Figure 6 Image of Functional Magnetic Resonance Imaging (fMRI) scanning. The participant in an fMRI study responds to images, sounds or other stimuli while lying in a scanner. Use of magnetic fields to monitor blood flow in the brain yields information about which brain regions are active.

The patterns of brain activity revealed by fMRI may differ in people with autism, compared to the neurotypical population. For instance, there may be reduced activity in a brain region called the **fusiform gyrus**, which has a specialised role in face recognition, linking with the observation that autistic people find it hard to recognise faces which they have seen before.

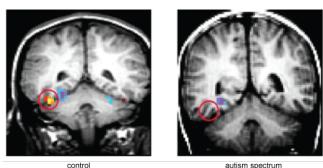


Figure 7 Images of fMRI scans of an adolescent male on the autism spectrum (right) compared with an age- and IQ-matched typically developing control (left).

Atypical patterns of brain activity are also observed when autistic people perform tasks such as the 'Reading the Mind in the Eyes' test illustrated earlier.

(See Lai, Lombardo and Baron-Cohen, 2013, for an overview of findings like those discussed in this section.)

4.2 Neurons, neurotransmitters and hormones

Other brain studies focus at the level of nerve cells or **neurons** and other microscopic components of the nervous system. The millions of neurons which transmit messages within the brain and nervous system form a dense network of connected fibres. One current idea is that the overall pattern of this connectivity is different in the autistic brain, with some areas being unusually densely connected, and others sparsely connected (Wolff, 2012, cited in Hughes, 2012).

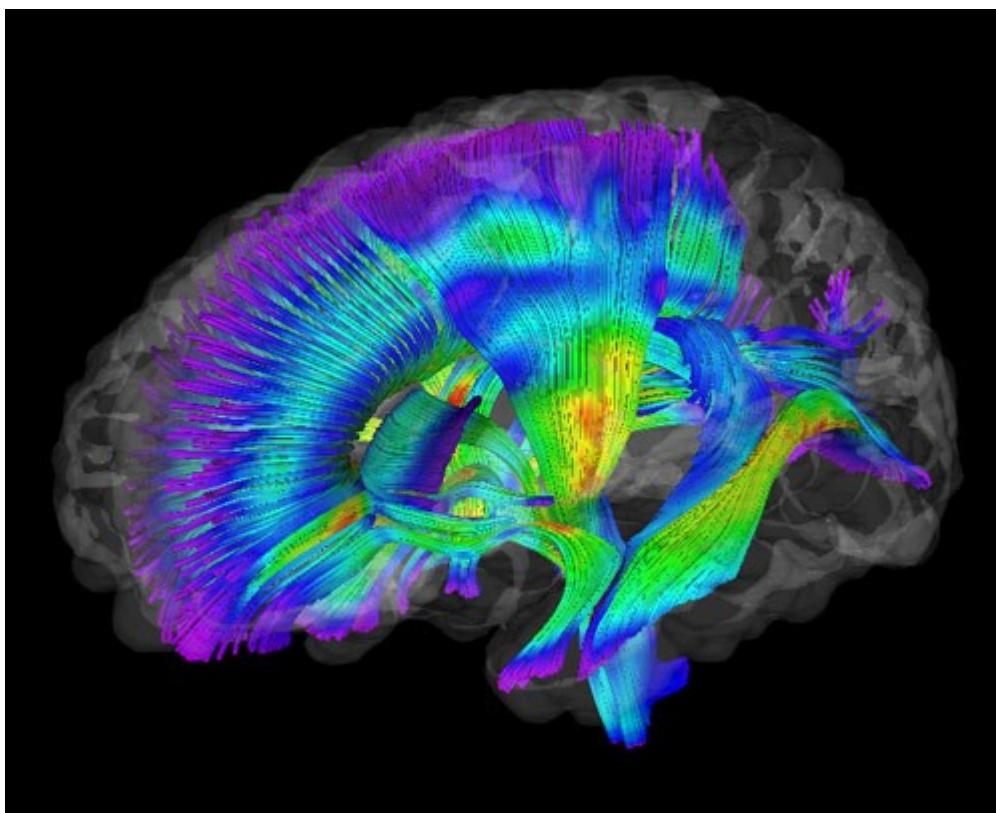


Figure 8 Different areas of the brain are profusely connected by complex networks of neurons. The pattern of connectivity may be different in autism.

There is also some evidence that the structure and functioning of **synapses** (the minuscule gaps between neurons) differs in autism. Messages are transmitted along nerve fibres by minute electric currents, but crossing the synaptic gaps involves chemical messengers called **neurotransmitters**.

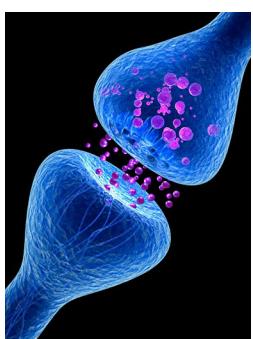


Figure 9 Schematic image of a synapse with molecules of neurotransmitter carrying messages across the synaptic gap.

Some studies suggest that some autistic people have higher than normal levels of a neurotransmitter called **serotonin** in their blood, suggesting an overproduction within the brain. Medical drugs which are known to influence serotonin uptake in the brain can have an impact on anger and repetitive behaviour in autism.

Finally, different levels of certain **hormones** have been reported. Hormones are another type of chemical messenger, which play an important role in bodily and brain function. For instance, when you experience a stressful situation, adrenaline is released which causes perspiration, raised heart rate and other 'fight or flight' reactions. **Oxytocin** is a hormone which is known to be important in social relations, and some studies report lower levels in children with autism. Some studies suggest that administering extra oxytocin to autistic people via a nasal spray may help with emotion recognition skills.

If you are interested to learn more about the brain and nervous system and how they are implicated in autism, you may like to look at parts of this optional interactive activity:

You can find an [downloadable interactive brain activity at this link](#).

You can find [instructions for downloading and using the interactive brain activity at this link](#).

5 The genetics of autism

Both the psychological characteristics of autism and underlying neurobiological atypicalities are thought to be linked to genetic influences.

5.1 Autism in families

As you learned in Week 1, twin studies provide evidence for a strong genetic factor in autism. When one twin of a pair is on the autism spectrum, the chance of the other twin also being on the spectrum (known as **concordance**) is much higher if these twins are identical than if they are fraternal. Identical twins have identical genes, whereas fraternal twins are no more alike genetically than, say, two brothers or two sisters. Identical twins and fraternal twins are likely to be very similar in their experiences of the environment. Therefore, the higher concordance for autism in identical twins suggests that the predisposition to develop autism is strongly genetic.

Even in non-identical twins or in siblings, concordance for autism is higher than in the neurotypical population. Twin and sibling concordance findings together suggest that autism can be passed down (inherited) from one generation to another, and affect multiple members of the same family. This was illustrated in video clips in Week 3: brothers Acis and Harry and their grandfather John are all on the autism spectrum.

5.2 Genes and chromosomes

Genes are commonly referred to as the ‘blueprints’ for life – the basic units of **heredity**, which means the passing on of physical and behavioural traits from one generation to the next. Differences in, for example, our eye colour or hair structure are due to differences in genes we inherit from our parents. Genes are small sections of very long molecular structures called **deoxyribonucleic acid (DNA)**. DNA has a precise sequence of units, with a section of these units together constituting a gene.

Each gene contains the instructions for making a specific protein which in turn instructs our cells and tissues how to interact, grow or respond to damage and diseases. For example, there is a gene containing instructions for making the hormone insulin, a substance with an important role in regulating our blood sugar level. While we each have a gene that codes for insulin, the precise sequence of units within that gene can vary between individuals. Such differences, known as **DNA variants**, may cause differences in the way a protein functions.

Genes are organised into 23 distinctive pairs of structures called **chromosomes**, carried within the cells of our body, and visible down a microscope (Fig. 10). Of each pair of chromosomes, one is inherited from the mother and one is inherited from the father. The first 22 pairs of chromosomes look the same down the microscope for men and women. The last pair are the sex chromosomes. The body cells of males have one copy each of the X chromosome and the (much smaller) Y chromosome, while the cells of females typically have two X chromosomes.

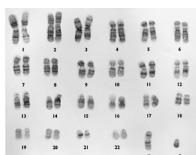


Figure 10 Photograph of the 23 pairs of chromosomes of a human male, from a light microscope image, magnified approximately 1000 times.

In humans, the 23 chromosome pairs hold tens of thousands of genes that together are known as the **human genome**.

Each of us inherits one member of each chromosome pair from each of our parents – but before they are passed on during sexual reproduction, material within each of these chromosome pairs crosses over during the formation of egg or sperm, part of a process known as meiosis (Fig. 11). Natural breakages occur on each paired chromosome, shown here at the white line two thirds of the way down, and a section of genetic material is exchanged such that novel combinations are formed. Each egg or sperm inherits just one of these paired chromosomes which includes a novel combination of material from each parental chromosome.

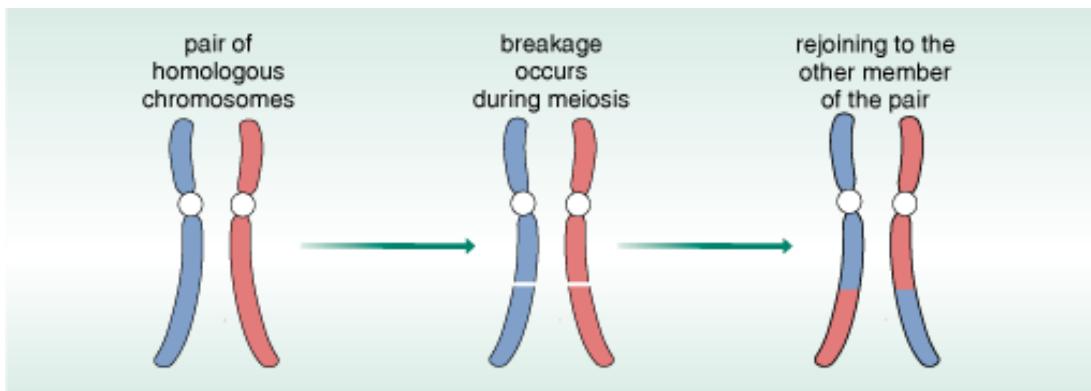


Figure 11 A chromosome pair before, during and after the cross-over of genetic material that occurs during production of eggs and sperm.

The result is that offspring inherit combinations of each of their parents' chromosomes, and can therefore also exhibit characteristics of each parent, and of earlier generations (Fig. 12).

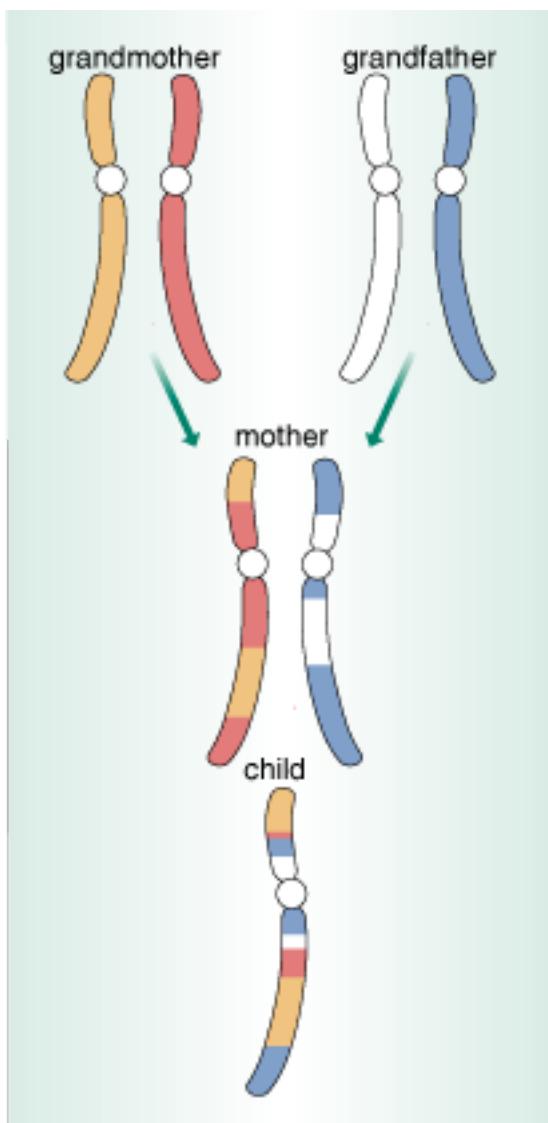


Figure 12 The effect of crossing over on the arrangement of genetic material along chromosomes, shown across three generations. The three colours represent the different origins of the genetic material in the chromosomes of the grandparents, and how a grandchild thus inherits a mix of genetic material from both grandparents.

During egg and sperm formation, and during breakage and rejoicing of the parental chromosomes, additional changes to the genetic sequence may occur. Such '**mutations**' give rise to new DNA variants which may contain altered instructions for protein development. This may in turn trigger differences in the way the brain and nervous system develop, which are then passed on to further generations

5.3 Autism genetics are complex

In autism, links are proposed between particular genetic variants, atypical development of the nervous system including the brain, and behavioural differences such as theory of mind difficulty and repetitive tendencies.

However, this is a complex and speculative field. Whereas certain conditions (e.g. cystic fibrosis) result from mutation of just a single gene, autism (except in fairly rare cases) involves the combined effects of variants in many different genes – it is said to be

polygenic. Also, this combination of genes and variants may vary from one person or family to another, so autism is said to be **heterogeneous**. Researchers have found **candidate genes** (genes that may potentially transmit susceptibility to autism) on a very large number of chromosomes.

Besides this complex pattern of genetic influences, the **heritability** of autism (the extent to which it can be attributed to genetic factors) is not 100%. A parent may be on the autism spectrum without his or her children inevitably having autism. A child may develop autism without a family history – their genome may be altered by a new mutation, for instance arising during egg or sperm production, or by **epigenetic influences**, which control the action of certain genes. Other non-genetic factors may also influence the development of autism. For instance, exposure in the womb to Valproate, taken by a mother as epilepsy medication, may increase a child's risk of developing autism (Christensen et al., 2013). Influences such as these, thought to affect the prenatal environment of the developing foetus, are not well understood at present.

(See Lai, Lombardo and Baron-Cohen, 2013 for an overview of autism findings like those discussed in this section)

This week's quiz

Now it's time to complete the Week 4 badge quiz. It is similar to previous quizzes, but this time instead of answering 5 questions there will be 15.

Remember, this quiz counts towards your badge. If you're not successful the first time, you can attempt the quiz again in 24 hours.

[Week 4 badge quiz.](#)

Open the quiz in a new window or tab then come back here when you're done.

6 Summary

This week has looked at key explanations of autism at three different levels: psychology, neurobiology and genetics. Psychological research has highlighted processes (theory of mind, executive function, etc.) which may help to explain observed behaviour and thinking style in autism. But no theory is conclusive, the findings vary, and in particular sensory differences have proved difficult to explain. There is copious research into brain and nervous system differences and genetic influences related to autism, but again, no firm conclusions can be drawn.

Next week deals with the very different question of how autistic people can be helped.

You should now be able to:

- understand key approaches to explaining autism
- differentiate three levels of explanation: psychological, neurobiological and genetic
- understand key psychological accounts of the autistic 'thinking style' and identify implications for everyday life
- appreciate key ideas about brain and nervous system function in autism
- appreciate the complex role of genetic influences in autism.

Now you can go to Week 5.

Week 5: Addressing challenges: approaches to intervention

Introduction

This week opens by considering the goal, sought by some people and vehemently rejected by others, of a ‘cure’ for autism. **Interventions**, the main focus of this week, are presented not as ‘cures’, but as procedures to help autistic people overcome challenges in order to promote development and quality of life. The framework for evaluating interventions in relation to evidence is explained. A small selection of key interventions are outlined, including some recent developments in the field.

Now watch the following video in which Dr Ilona Roth introduces this week’s work.

Video content is not available in this format.

By the end of this week you should be able to:

- appreciate contrasting views on ‘curing’ autism
- understand what is meant by ‘intervention’
- appreciate the importance of interventions being evidence-based
- understand broad principles for evaluating interventions
- be familiar with key interventions and recent developments in the field.

1 Perspectives on recovery and help

The first priority for many parents of an autistic child or adult is to secure help and support. Some parents, and clinicians too, go further, seeing autism as something to be ‘cured’ or eradicated. An objection to this idea, from a neurodiversity perspective, is that autism should be seen as a difference, not as an illness or disability which needs ‘curing’. Even if aiming for a cure is seen as acceptable by some, since autistic children’s communication, social and thinking skills start to diverge from the typical developmental pathway at an early stage, reversing these changes poses a big challenge.

1.1 Optimal outcomes

Some recent research does provide provisional evidence that a small proportion of autistic children achieve an '**optimal outcome**' in adulthood (Fein et al., 2013). This means that their symptoms have modified to such an extent that they no longer meet the diagnostic criteria for autism, though they may retain subtle differences in thinking style. The research suggests that such an outcome is most likely following early intensive treatment or intervention. However, it is not yet clear what characteristics distinguish those who achieve an optimal outcome from those who do not. You will read more about this in Week 7.

Of course, the idea of an optimal outcome could also be seen as disrespectful to autistic people – who is it that decides what an 'optimal' outcome is? Alex, whom you have met in earlier weeks, has overcome many challenges while growing up, and leads a full life, studying, working and driving his own car. In this clip, he reflects on strengths that are part of his identity as an autistic person.

Video content is not available in this format.

1.2 Contrasting views on acceptance

More able autistic individuals may be more likely to oppose the idea that the differences which make them who they are, need to be removed. And some may even reject the need for any form of help to address their challenges. Parents of more severely affected children, who face profound challenges and difficulties for themselves and their family, are more likely to seek help, and perhaps even to pursue recovery. However, this differentiation is not always correct. The journalist Charlotte Moore, who has two children with a severe form of autism, wrote:

I hope I was never looking for a cure; now, I'm sure I'm not. I want Sam to stop scattering his food and biting his hands, but I don't dream of a neurotypical Sam with the usual emotional and intellectual range of a boy of 11, because no such Sam could possibly exist.

(Moore, 2003)

Charlotte prefers to accept her sons' autism as a different way of being, while acknowledging that there are challenges which it would be desirable to overcome.

Arabella, mother of Iris Grace, expresses her views in this clip.

Video content is not available in this format.

2 Interventions

Even without help, an individual's profile of skills and behaviours is likely to change over time, and in adulthood some difficulties may become less severe or apparent. However, key symptoms and difficulties typically persist and may even become more marked, with an enduring impact on the person's lifestyle and well-being. It is generally believed that identifying autism and intervening as early as possible is most likely to have a beneficial effect (Howlin et al., 2009). An intervention is a technique or procedure to support and help children or adults with autism to engage with others and to thrive, for instance by helping a non-verbal person to communicate, or a highly anxious person to reduce their anxiety. While this means adapting to the neurotypical world, it is equally important that the neurotypical world becomes more accepting and tolerant of autistic behaviour, and better adapted to autistic needs. Organisations like the National Autistic Society (NAS) are active in promoting this goal. You will read more in Week 8.

A range of interventions has been developed, targeted at different problems and different groups. Many of these interventions are for children, especially those with low-functioning autism including marked language and intellectual disabilities, and are designed for use in home and educational settings. Although individuals with high-functioning autism or Asperger syndrome have better language and intellectual skills, they may face challenges in interacting, behaving flexibly, and in other everyday skills, which also call for support throughout life. Some interventions lend themselves well to supporting these more able groups, and also the needs of adults.

2.1 The importance of evidence for interventions

Before they are tried out, interventions should be evaluated in terms of their rationale, safety and likely chances of success. Careful **evaluation** of evidence is fundamental to the framework of sound clinical practice known as **evidence-based practice**. Whether altered behaviour or improved skills learned through an intervention will readily **generalise** i.e. carry over to contexts different from those where they were acquired, and whether they will apply to others with autism too, are further important considerations. Before looking at what goes into an evaluation, we will briefly consider the risks of intervening without adequate rationale or evidence.

2.2 Intervening without evidence

From time to time, interventions for autism are proposed with an odd or unconvincing rationale, little or no evidence, and often with grossly exaggerated claims for success. Parents of autistic children may be highly vulnerable to claims for a 'cure', 'recovery' or dramatic alleviation of symptoms, and understandably, they also feel empowered by doing anything they can to help their child, even if only on the principle of 'try anything if it might help'.

One such approach, known as **packing therapy**, has been promoted in France, where some ideas about autism still remain far from those that are widely accepted elsewhere. The child is first wrapped in towels soaked with cold water, and then with blankets to warm the body. The claim is that this develops consciousness of bodily limits, which, according

to proponents of the therapy, is lacking in autism. There has been widespread condemnation of this ill-founded practice, which has been described as 'a form of child abuse and a gross violation of basic human rights' (Research Autism, 2018).

Another ill-conceived approach assumes that autism is caused by excessive levels of toxins such as mercury and lead in the blood. The 'therapy', known as **chelation**, involves administering substances to eliminate the 'excess toxic substances' from the blood-stream. However, chelation has proved to have extremely harmful side effects and in 2005, an autistic child who was being treated in this way died of a cardiac arrest. In 2013, the National Institute for Health and Care Excellence (NICE) published the following statement:

Do not use [chelation] to manage autism in any context in children and young people

(National Institute for Health and Care Excellence, 2013)

These two techniques provide just two examples of highly dubious interventions. Imagine you had a child with diabetes, and someone offered you a previously unknown medication which they claimed provided a highly effective cure. Before trying out such medication, you would want to know how and why the substance was supposed to work, you would need evidence that the substance actually worked, and assurance that it did not have harmful or dangerous side effects. You would also want to know more about the person promoting the cure, such as whether they had a financial interest in it. The importance of addressing questions like these applies equally to autism as to treatments for medical ailments. Interventions for which the rationale is unclear, and which lack proper evaluation or ethical screening are quite rightly avoided or treated with great caution.

3 Establishing the evidence base for interventions

Deciding whether an intervention works might seem like a relatively straightforward process of trying the approach with one or more autistic participants, to see if it helps to address particular challenges or difficulties, or promotes 'positive' aspects of behaviour. However, evaluation is never this simple or straightforward.

3.1 Principles of evaluation

Activity 1 Reflecting on the principles

Allow about 10 minutes

Imagine that you are a practitioner considering a new intervention developed by a team of researchers and practitioners, who claim successful evaluation of their procedure. What questions would you want to be sure had been addressed? Drawing on the earlier discussion in Section 2, note three or four key points.

Provide your answer...

Answer

Here is a list of major considerations:

Rationale

Does the suggested intervention draw upon theory and/or previous research about autism which helps to explain how and why it might work?

Focus

What specific problems, behaviours or skills is the intervention supposed to target? (e.g. if communication, which aspects?)

Ethics

Does the suggested intervention avoid unpleasant or dangerous side effects? Does it safeguard the well-being of participants?

Were the researchers who conducted the evaluation independent of the group involved in developing and promoting it?

Method

Participants: has the procedure been tested with an adequately sized group of participants, all with a verified autism diagnosis?

Have specific procedures for the intervention been clearly defined, and rigorously followed during the study?

Criteria for 'success': what measures or findings indicate that targeted behaviour has been reduced or enhanced?

Outcomes

Do any changes which come about actually result from the procedure? (They could occur by chance or due to some other factor.)

Would the intervention generalise, that is be effective long-term and if administered in 'real-life' settings?

There has been increasing emphasis in recent years on the need for interventions to be fully evaluated, to avoid harm, and to comply with the principles of evidence-based practice. In an ideal situation, evaluation should commence with relatively small-scale informal tests, and build up to more formal and wide-ranging evaluation, as outlined next.

3.2 Pilot and small-scale studies

The initial stage of evaluation is an exploratory or **pilot study** in which the proposed intervention is tried with just a few autistic individuals. Of course, full ethical safeguards must be ensured, and the participants (or parents on participants' behalf) must give their consent to participation.

If a pilot study suggests a positive effect, a more formal, **small-scale evaluation** can be carried out. Again this may involve just a small group of participants, who are observed for a period before the intervention, while it is carried out, and for a period of time afterwards. A common procedure for this is a **multiple-baseline study**. Each participant is observed for a period before the intervention to establish a baseline for the behaviour to be targeted by the intervention e.g. how often the child communicates verbally. The length of the observation period is varied such that the intervention start date is staggered across participants. This makes it easier to ascertain that any change, such as more verbal communications, is due to the intervention itself. If all children started the intervention

simultaneously, they might all experience another new factor (e.g. a change of teacher) which could be causing any changed behaviour.

3.3 Controlled studies and randomised control trials

A **controlled study** is a more rigorous and formal evaluation of an intervention similar to a research experiment (see Week 1). The study typically involves two groups of participants on the autism spectrum, both larger than those used in pilot and small-scale evaluations. One group (the experimental or **intervention group**) receives the intervention, and the other (the control group) does not, or they receive another intervention already known to have some effect. The latter procedure is known as '**treatment as usual**'.

Ideally the two participant groups in the study should be matched on criteria such as age, IQ or severity of symptoms, before the intervention begins. After the intervention period, the two groups are compared to see if there are any differences. This comparison requires a specific measure of the skills or behaviours that the intervention is designed to target, known as the **outcome measure**.

Activity 2 Principles of controlled evaluation

Allow about 5 minutes

In a controlled study, one possible way to evaluate the effect of the intervention is for the control group to receive no intervention at all. However, the 'treatment as usual' procedure just outlined is more usual. Suggest one or more reasons for this.

Provide your answer...

Answer

Offering an alternative 'treatment as usual':

- reduces the likelihood that parents, or control participants themselves, will lack motivation to be involved. This could affect recruitment, and/or the outcomes in the control group
- helps to address ethical issues: there is a good chance that everyone will gain some benefit from the study, whether in the new intervention or in the 'treatment as usual' group
- enables the new intervention to be compared with existing interventions, to see if it is more or less effective.

Another ideal procedure for a controlled study is that participants are assigned randomly to treatment and control groups – much like drawing numbers out of a hat. This avoids factors which might bias the outcomes, for instance, that the participants in the intervention group are more high-functioning than those in the control group. The term **randomised control trial (RCT)** refers to a full-scale controlled evaluation involving random allocation to intervention and 'treatment as usual' groups, and a relatively large number of participants. RCTs are widely used to evaluate new medical interventions, and are also considered the 'gold standard' in the autism field. But to date, few evaluations of

autism interventions have been evaluated as far as the RCT stage. We will consider why next.

3.4 Problems in evaluating autism interventions

Taking a new intervention through a rigorous series of evaluations is usually lengthy and costly – to borrow another example from medicine, think of how long a malaria vaccination has been in development. In the knowledge that, in autism, intervening early in development is best, parents, teachers and even clinicians may feel that they cannot wait for the full outcomes of clinical trials. They may therefore resort to procedures known to be broadly helpful and not actively harmful. Unfortunately, some parents may also feel driven to try extremely risky procedures.

Another problem is the heterogeneity of autism. It may genuinely be the case that an intervention works for some individuals but not for others. In a formal control study or RCT, where relatively large participant groups are compared, there is the risk that benefits experienced by a small subset of the participants receiving the intervention are ‘averaged out’, such that the intervention does not appear to be beneficial overall.

As you will see, some well-established treatments depend crucially on adapting the goals and procedures to the needs of the individual child, making it very difficult to specify standard group procedures and outcome measures as required for an RCT.

3.5 The Research Autism database

A UK information service, Research Autism, has a [database](#) offering accessible and impartial guidance on as many as possible of the known interventions for autism, including a description of each approach, and a grading across the range from strongly positive to a warning that the intervention could be harmful (Research Autism, 2018). The evaluations, made by experts commissioned by Research Autism, are a valuable and authoritative source, whether for researchers and practitioners seeking a quick update, or for parents and individuals with autism, who may not have access to the full academic literature concerning evidence for interventions.

Activity 3 Getting to know the Research Autism website

Allow about 10 minutes

Use the following link to access the list of interventions which have been evaluated by Research Autism. Have a look at the description and evaluation of the different interventions and locate ones which have these symbols next to them:



Hover over the symbols on the website and note down what they mean. Here's the link:

[Our Evaluations of Autism Interventions, Treatments and Therapies](#)

Answer

Two ticks next to an intervention indicates that there is 'strong positive evidence' to suggest the intervention is effective. If you click on the specific intervention, you will find out more about that intervention and its benefits.

A question mark means that the evidence for the intervention is mixed or insufficient.

An exclamation mark indicates that the intervention risks physical and/or psychological harm to people who experience it. Research Autism advises that the procedure should not be used.

The next sections outline some well-known and widely used interventions for autism, followed by some recent developments in the intervention field. Note that while none of these interventions is considered risky in application, the level of evidence varies, and at least one of these approaches attracts widely polarised views among practitioners. Most of these interventions are included in the Research Autism evaluation list, and you will find reports on the others elsewhere on the Research Autism website.

4 TEACCH

TEACCH is the acronym for the Treatment and Education of Autistic and Related Communication Handicapped Children. The approach was introduced in the 1970s when the term 'handicapped' was not deemed unacceptable as it is now. TEACCH has been effectively used in many countries since then and is recommended by the NAS and the Autism Society of America (ASA). It is a 'whole person' approach in that it aims to support many aspects of functioning, including learning, behaviour, social and communication needs, and may be used across different settings (at home, school, in respite services and other locations) as well as across the person's lifespan. It can also be successfully adapted for more intellectually able individuals, and used in adult settings.

4.1 Principles of TEACCH

The TEACCH framework aims to maximise an individual's strengths, drawing on how autistic people tend to think and to engage with the world. Here are some key principles:

- emphasis on structure, including physical structure of the person's environment and clearly defined routines
- harnessing skills; for instance visual skills and good memory for factual information mean that a visual schedule indicating what activities will happen, where and when, is likely to be an effective tool
- evaluation of individual support needs on a regular basis, including use of other interventions where necessary to complement the approach
- empowering parents by encouraging their full participation
- emphasis on developing independence, and generalising from learning experiences in order to master a range of everyday situations.

Patrick's planner		Tuesdays - Autumn Term
ACTIVITY	NOTES	
Registration activity	Today is Tuesday. Read your planner to check your day	
English	Working from English Alive book (IEP Target)	
Break	Choice time	
Maths	Community based learning activity (IEP Target)	
Lunch	Today lunch will be in the leisure area	
PE	Aerobics (Inclusion Target)	
Break	Make yourself a drink	
History	Inclusion Target: 20 minutes with Mr Subramanian (Subject Teacher)	
Review	Did you eat lunch with Edgar today? What book are you reading?	
Club	Board game with Srishti in your room	
Home	Your taxi driver is Pauline	

Figure 1 Clear structure and visual information provide the basis for a planner to help a child with their day at school.

4.2 Evidence base for TEACCH

TEACCH has a clear and appropriate rationale, in that it addresses the characteristic need for structure and routine in autism. Research Autism reports a 'small amount of high quality research evidence for TEACCH', pointing to an impact on social communication, cognitive and motor skills. However, to date there have been no RCTs or large-scale evaluations. The fact that it is specifically tailored to the challenges experienced by an individual child or adult means that it is not easy to identify outcome measures appropriate for all participants in a study, nor to set up control groups. It is likely that outcomes will be affected by the skill and expertise of the professionals involved. There is also evidence that when or if TEACCH is withdrawn, an autistic person may regress in their behaviour and anxiety levels, or be unable to generalise what they have learned to new contexts.

5 The behavioural approach to intervention

A quite different approach to intervention originated in the work of Ivor Lovaas, described in Week 1. He in turn drew on the work of mid-twentieth century psychologists such as B. F. Skinner, who proposed that in animals, including humans, the repertoire of behaviour can be modified and new behaviours learned, using **operant conditioning**. Operant conditioning assumes that active behaviour 'operates' on the environment, with consequences that modify whether the behaviour is repeated in the future. If the consequences are rewarding, the behaviour is more likely to be repeated – known as **reinforcement**.

5.1 Applied behavioural analysis

Lovaas' approach evolved to become **Applied Behavioural Analysis (ABA)**, an intervention for autism in which operant conditioning principles are used to reinforce 'desirable' behaviours (e.g. more speech and communication) and reduce 'undesirable' behaviours (e.g. aggressive or repetitive behaviours that may be injurious or considered antisocial, such as head banging, destruction of objects or taking clothes off in public).

In ABA the child's behaviour is analysed into components that are tackled one at a time. If the target behaviour is one that it is identified for the child to learn, for instance uttering a word or phrase, the reinforcement needs to be a positive outcome for the child, such as a favourite snack or some non-edible reward. If the behaviour is something that it is thought should be discouraged, for instance a tantrum, then withholding reinforcement (e.g. by ignoring the behaviour, saying 'no' loudly and firmly, removing the child from the context or reinforcing alternative behaviour) should eventually result in the behaviour disappearing.

The first stages of ABA may focus on teaching self-help and receptive language skills (i.e. language understanding), non-verbal and verbal imitation, and the foundations of appropriate play. The second stage emphasises the teaching of expressive language and interactive play with peers. Advanced stages involve the learning of early academic tasks, socialisation skills, cause and effect relationships, and learning by observation. The intervention might seem particularly relevant for young children who are lacking basic communication skills and everyday capabilities. However, children with higher initial intellectual ability and less pronounced autism are also said to make good progress, especially following early behavioural intervention. ABA is also used with some autistic adults.

If at all possible parents are trained to carry out ABA at home, albeit supported by trained therapists and consultants. Classic ABA approaches stipulate that 40 hours per week should be spent on 'shaping' the child, making it expensive for parents or local service providers to employ trainers. The commitment for parents is also substantial.

5.2 Evaluations and views of ABA

ABA has been difficult to formally evaluate for two reasons. Firstly, like TEACCH, it is a highly individualised approach, with outcomes that are tailored to the behaviour of an

individual child. Secondly, ABA is no longer a single unified approach, but rather a set of varying procedures, some of which have also been incorporated into other types of intervention.

Attitudes to ABA among families and professionals are sharply divided. Proponents of the approach argue that it is one of the few really effective treatments, which can make dramatic improvements including the potential to develop language skills in non-verbal children. An early intervention based on ABA principles, known as **Early Intensive Behavioural Intervention (EIBI)**, has been evaluated as particularly effective (Peters-Scheffer et al., 2011). One criticism of ABA claims that it is a simplistic tool, which changes 'surface' behaviour rather than underlying thought processes. The fact that parents and therapists decide what behaviour should be shaped has led to the further criticism that ABA is '**adult-directed**', taking away the child's autonomy, choice and dignity (Devita-Raeburn, 2016). ABA also requires a level of dedication and expense that makes it inaccessible to some families.

Bear these contrasting viewpoints in mind while watching this clip illustrating how a young boy called Joe is helped with his communication skills by therapists using Applied Behavioural Analysis. Watch this clip now.

Video content is not available in this format.

6 Naturalistic interventions

In contrast to how adults identify the ‘desirable’ behaviour within ABA, approaches have been developed which build upon the child’s own interests and preferences. The role of the teacher or therapist is to prompt or encourage natural communicative behaviours which are initiated by the child. These approaches are known as **naturalistic interventions**, and they are all, to a greater or lesser degree, **child-centred**.

6.1 Picture Exchange Communication System (PECS)

The best known and most widely used naturalistic intervention is the Picture Exchange Communication System (**PECS**). This was devised in the 1990s with the aim of teaching functional communication skills, especially to autistic children with little or no language. Each child is individually assessed to identify objects and activities that he or she finds rewarding, and a booklet or board of small pictures is compiled matching the child’s preferences.

The child is then guided through different stages towards the goal of making spontaneous requests for these items, one adult acting as a communication partner and a second adult as the child’s physical prompter. As the child reaches for a desired object, the physical prompter then physically guides the child to pick up a picture of the object and release it into the communication partner’s hand. The physical prompter gradually reduces the prompting as the child becomes more independent in selecting pictures of what he or she wants, and exchanging them for the object itself.

Once the child is using pictures in spontaneous communicative exchanges, PECS intervention aims to strengthen this spontaneity and to enhance the child’s ability to distinguish between pictures, increasing the number available to them, firstly from a board and then from a folder. The child is also encouraged to generalise his/her new-found communication skills to different settings and communication partners, to produce more complex communications, and eventually make comments about things they see rather than just requesting things they want.

Watch the following video clip which illustrates the use of PECS in classrooms Queensmill School in Hammersmith. Notice that these children have reached the stage of combining pictorial symbols with phrases such as 'I want', and sometimes saying the sentences out loud. Look carefully at how the communication partners are using PECS in these clips, and keep this in mind for Activity 4, coming up in the next section.

Video content is not available in this format.

6.2 Evaluations of PECS

PECS is one of the few autism-specific interventions to have been evaluated through all of the stages described earlier, including some RCTs. For younger children with little functional speech there are positive findings, especially increased social communication.

PECS is widely used, although further research is needed to establish which children on the spectrum are most likely to gain maximum benefit from using it. Unlike ABA, PECS is easy and cost-effective to administer. However, Research Autism stresses the importance of training to ensure correct implementation.

Activity 4 PECS in action

Allow about 3 minutes

In the clip you just watched, was there anything that didn't match the earlier description of how children are taught to use PECS?

Provide your answer...

Discussion

The teachers were serving as communication partners, but they were also prompting children who already had PECS skills. This may have been detrimental to developing the children's spontaneity. The challenge is to manage any child-specific adaptation of an intervention like PECS without losing the core procedures which make it effective.

7 Recent developments in intervention

In the last few years, new approaches to intervention have emerged, some building on the classic approaches already described, and others completely novel. A small selection is featured here.

7.1 Pre-school Autism Communication Therapy (PACT)

The **PACT** approach trains parents to work on enhancing the communication and language development skills of their own children, commencing as early as possible after diagnosis (Green et al., 2010). Parents view video footage of their interactions with their child and are taught to adapt their own communications in order to respond with enhanced sensitivity and responsiveness, for instance using eye gaze, sharing, showing and giving to increase shared attention. Parents learn to tailor their language use to the child's level of understanding and to facilitate child communication and participation, for instance through sequences of actions, repeated verbal scripts and the use of elaborations, pauses, and playful teasing.

7.2 Evaluations

In 2010, an RCT (also known as PACT, the Pre-school Autism Communication Trial) reported that children whose parents received the training were using words and gestures more often than those in the control group. In 2017, a 'follow-up' study showed that these benefits had persisted. Children also showed enhanced social skills and fewer repetitive behaviours.

The approach is attracting considerable interest because of the substantial number of children involved in the RCT, and the retention of positive outcomes over the longer term. The successful use of parents as therapists also has the benefit of being naturalistic and cost-effective, making the intervention a good choice for low and middle income countries. A culturally appropriate version of PACT is being trialled in India (Divan, 2017). Given the dearth of available specialists in India, the approach was adapted to enable lay people to train parents. Though viewing videos of themselves was challenging for some parents, they came to value the guidance. One mother commented that the approach was 'making a change in my child, but also making a change in me' (Divan, 2017). RCTs of the Indian initiative are underway.

7.3 Assistive technology

There is rapid growth in **assistive technology**, the use of technology, and especially IT, to help autistic people. This is a massive field, of which only a brief summary can be given here. Smartphones, tablets and computers have all been harnessed to help autistic people deal with problems of daily living, learn social and communicative skills, and in other ways. One important strand is the development of smartphone 'apps' designed to help autistic people with daily living skills. For instance, an able young person may

become anxious and confused if the bus they always catch to school is late or fails to come. A smartphone app could offer practical actions for such a situation, for example: wait 20 minutes and then call parents at home; check the bus timetable for other possible buses. In video modelling a child or adult learns a new behaviour, such as how to greet a friend, by watching it being modelled by someone on a computer screen. Some more traditional approaches, such as the visual schedule shown in Fig. 1, are now available in computerised versions. Finally, researchers have started investigating the use of robots to teach new skills, on the view that robots provide a particularly accessible medium for an autistic person to learn from. You will find more information about these approaches on the [Research Autism website](#).

7.4 Animal-assisted interventions

There have been some enthusiastic media reports and documentaries about **animal-assisted interventions**, for instance horseback riding or having a pet in the family home. Advocates claim that contact with animals reduces stress, helping children to focus their attention and communicate better, promoting learning and increased sociability. Arabella, mother of Iris Grace, reports that acquiring a Maine Coon cat, Thula, played a remarkable role in helping Iris to overcome hypersensitivities and anxiety, such as a sensory aversion to certain clothes and fear of water. In this clip, Arabella talks about how Iris changed and developed when Thula joined the family.

Video content is not available in this format.

7.5 Evaluations of animal-assisted interventions

A recent scientific overview of animal-based interventions in autism, while recognising that they may be beneficial for some children, concluded that the evidence is as yet unclear. Interpretation of studies is complicated by factors such as small participant numbers, and variations in the animals, procedures, duration of therapy and outcome measures (O'Haire, 2013).

Activity 5 Considering animal-assisted interventions

Allow about 15 minutes

Draw on the interview with Arabella and the Research Autism website to note two arguments in favour of animal-based intervention and two against. You should look up Research Autism entries for equine and dolphin therapies and assistance dogs.

For:

- 1.
- 2.

Against:

- 1.
- 2.

Answer

Points in favour:

1. Arabella suggests that contact with a cat helped Iris to overcome some sensory problems and other anxieties e.g. about travel.
2. The good relationship between Thula and Iris provided important respite for her parents.

Points against:

1. Some animal-based approaches such as swimming with dolphins could be harmful for the animal and harmful or frightening for the child.
2. Some improvements attributed to an animal like Thula may have taken place anyway. Since supportive evidence is so far sparse, the expense and effort of animal-based intervention may not be justified.

8 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 5 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

9 Summary

One message from this week is that no ‘one size fits all’, due to the diverse nature of autism. Increasingly psychologists are advocating a combination of methods, individually tailored to the person’s skills and needs. While many interventions do require training or specialist therapists, some adjustments can be implemented easily by families, schools or workplaces. For instance: removing, as far as possible, sources of sensory distress, such as fluorescent lights or noisy air conditioning; providing a secure place for when the person feels overwhelmed, or a ‘traffic light’ card system so that, at times when they feel unable to speak, they can signal positive or negative feelings with a green, amber or red card.

This clip from Arabella describes some of the strategies she has used to help Iris.

Video content is not available in this format.

You should now be able to:

- appreciate contrasting views on ‘curing’ autism
- understand what is meant by ‘intervention’
- appreciate the importance of interventions being evidence-based
- understand broad principles for evaluating interventions
- be familiar with key interventions and recent developments in the field.

Now you can go to Week 6.

Week 6: Family life and education

Introduction

This week considers the experiences and challenges of family life when one or more family members is autistic. The discussion starts with autistic children, considering initial experiences within the family, as well as the changes that occur as children grow and develop. The focus then moves to support for families and options for education. However, as you will see, access to these options is not evenly distributed across all families and groups. And beyond countries such as the UK, especially in low and middle income countries (LMICs), families may struggle to get any support or education for their child.

Now watch the video in which Dr Ilona Roth introduces this week's work.

Video content is not available in this format.

By the end of this week you should be able to:

- appreciate different ways in which family life may be affected when one or more family members is autistic
- understand how challenges for the family and for the individual with autism change over the course of development
- be aware of some of the sources of support available to families in the UK
- appreciate the psychological, academic and social challenges posed by education, and the main choices available in terms of schooling
- understand the rationale for different educational choices, including home education.

1 Family life

All members of a family are likely to be affected when a child receives a diagnosis of an autism spectrum condition. Of course, families may have concerns even before diagnosis, and may have developed ways of coping with a child whose behaviour does not fit typical expectations. On diagnosis, close family members are typically affected the most, because they engage with their autistic family member on a daily basis.

Parents may experience a range of emotions, including initial grief that the child is not neurotypical, but perspectives change. You may recall [the video clip from Week 3](#): after

the shock and grief of discovering that his son Zack was autistic, Mark realised that Zack was just the same person as he had been before diagnosis. Another parent describes her primary feeling as relief. Her son Louis was finally diagnosed with Asperger syndrome, ADHD and learning difficulties at the age of 6, after years in which Melanie had struggled to have her concerns taken seriously:

My feelings were of total relief ... after years of being told he was perfectly normal and behavioural management tactics would solve it. He was described as a 'whirling dervish' by the local paediatrician! Impossible to control his behaviour in any way. Diagnosis meant I could get a Statement at school. Phew! But I had to fight for it.

(Melanie, 2017, pers. comm.)

Siblings may also experience a variety of feelings, including resentment, embarrassment and guilt. However, research shows that siblings also come to see autism in the family as 'normal', developing close relationships with their autistic sibling(s) (Preece, 2014).

Members of the wider family such as grandparents may be a source of support, but also conflict (Hillman, 2007). For instance, they may have difficulty accepting the diagnosis, insisting that their grandchild will grow out of their difficulties. Some grandparents may even believe that the parents are responsible for their child's 'difficult' behaviour. In Melanie's case, her father's attitudes to Louis evolved from traditional ideas about 'dealing with bad behaviour' to providing support:

Grandpa (my Dad and the only grandparent on my side) took a while to understand that a good hiding wasn't going to work and finally rose to the challenge – [he was] enormously supportive to me. Most others in the family accepted it well. At last! An explanation!

(Melanie, 2017, pers. comm.)

1.1 Sources of stress in families

Parents are likely to experience substantial stress. For instance, they may have to manage difficult behaviour, such as their child's anger outbursts, self-injury or insistence on wearing the same clothes every day. Sometimes the desperation to find immediate solutions for young children's behaviour may not have the best long-term consequences, as Charlotte Moore, mother of George and Sam, freely admits:

To start with the basics – food. It's taken 20 years to get George and Sam to eat anything like a normal diet. Most autists get stuck on a tiny range of trusted foods – I wish I'd kept all junk at bay, so that the boys would have had to obsess over, say, chicken, brown rice and carrots rather than chocolate and HP sauce (George) or crisps and icing (Sam). I used 'treat' food to help them cope with stressful situations, such as travelling or going to a party. Once they knew such treats existed they held out for them. Now, I would avoid such situations.

(Moore, 2012)

The challenges faced by families vary depending on the age of the autistic child and their cognitive skills, such as whether they use spoken language. A child who has difficulty

communicating may appear angry towards others or seek isolation, when the underlying problem is **sensory overload**, or frustration at not understanding what is going on around them.

Some children are hyperactive and impulsive. Other family members may have to adapt to not having spontaneous activities because of the autistic person's need for structure and sameness.

We started to avoid group activities as G couldn't join in, not understanding how to engage and interact. Swimming, music, even group speech therapy became inaccessible. I will never forget the speech therapist leading the group, taking me to one side and gently suggesting that G wasn't benefitting and was disruptive to the group. I left the room and we went to feed the ducks, which ended up with him eating bread and me sobbing through my sense of abandonment, hopelessness and isolation.

(N, 2017, pers. comm.)

Lack of sleep is also a significant issue. Children with autism often have disrupted sleep patterns, and inevitably this affects parents too. Jacqui Jackson is a single parent of seven sons and daughters, several of whom are on the autism spectrum. In 2006, when her family was still very young, Jacqui commented that she often went for several nights without sleep, and only took cat-naps on other nights. She was trying to write her PhD thesis at the time.

Physically it does take its toll ... It gets you down and it affects how you work.

(Elliott, 2006)

1.2 Multiplex families

Given the strong genetic influences in autism, it is not unusual to find families like Charlotte Moore's or Jacqui Jackson's, where more than one offspring has an ASC diagnosis. These are known as **multiplex families**.

Sometimes, when a child is being diagnosed, a parent, or even a grandparent, realises that they too are 'on the spectrum'. You may recall from Week 3 that John Peters received a diagnosis at the same time as his grandsons were being assessed, which helped him to find an explanation for the problems he had struggled with all his life.

Knowing that there is more than one person with autism can make family life less difficult, as the whole family can more easily adjust to living in an 'autism-friendly' way. Jacqui Jackson comments on the loyalty that her three teenage daughters show to her sons:

The boys are their yardstick. If someone can't accept them, then that person's not worth bothering with. Rachel had a boyfriend who called them 'spackers' and she dumped him pretty quick. The lad she's seeing at the moment loves Ben, in fact they fall out over him: 'You come to see Ben, not me!'

(Moore, 2003)

1.3 Adolescence

Adolescence often presents new challenges for young people with autism and their families. Hormonal changes can be difficult for any teenager, but especially so for the young person with autism, who may struggle to understand their changing body and emotions. They may have difficulties understanding their own sexual feelings, and misunderstand social norms concerning the development of friendships and romantic relationships. Neurotypical teenagers can be quite 'cliqueish', excluding anyone who doesn't conform to their way of doing things. Consequently, this is a life-stage when experiences of rejection, isolation or bullying are likely to be particularly prevalent, and is possibly why young autistic people are especially prone to mental health problems such as depression and anxiety (Picci and Scherf, 2014).

Picci and Scherf argue that the problems facing the autistic adolescent concern more than the challenges of social relationships. They suggest that around 30 per cent of autistic adolescents show an overall deterioration in their level of functioning in adolescence, and attribute this to a 'second hit' of difficulties affecting the brain and cognitive processes, accentuating weak central coherence and executive function problems (see Week 4). One consequence is that young people with autism often have difficulty with autonomy – that is, making decisions and performing everyday tasks. Despite these challenges, Claire Bachman, an American student with Asperger syndrome, is living independently from her parents and attending college:

As I transition to adulthood, I find it particularly challenging to do things such as daily chores on my own. I struggle to remember to take care of myself by bathing, brushing my teeth and the like. I was so used to my parents either doing things for me or reminding me to do them. Getting myself prepared for the day, looking for what to wear to school or to meetings, activities or events has been challenging. I am often not sure which outfit is appropriate, professional or acceptable.

(Bachman, 2016)

1.4 Adulthood

A lack of autonomy is especially prevalent in autism compared with other developmental conditions such as Down syndrome (Esbensen et al., 2010). While more profoundly affected adults may gain a residential placement, many autistic adults continue to live with their parents.

Since adult-focused services are very sparsely available, parents and/or other family members typically find themselves with multiple responsibilities, ranging from everyday care to negotiating benefits and seeking employment opportunities for their autistic family member. Even the most able autistic adult is likely to struggle with tasks such as form-filling. A family will need to deal with such administrative tasks, as well as acting as advocate in relation to officialdom. Parents may find themselves torn between caring for their own ageing parents and their adult child. As time passes, parents themselves are likely to become less able to care. This may then impact on siblings, who by this time may have children of their own.

You will learn more about the situation of autistic adults in Week 7.

1.5 Family resilience

Families with one or more autistic members have often been noted as developing **resilience**, becoming stronger and more resourceful. This comes from flexibility in accommodating the autistic person's needs and from good communication with each other. While every family's journey with autism is different, they have in common learning to appreciate the smallest of achievements and developing greater awareness of, and compassion towards, individual differences.

Life has never been the same since Matthew made his appearance in 2000.
Everyday activities that people take for granted, are a challenge in my house ...

Despite the pressure put onto us as a family, this has now become a way of life and we know no different. We feel that ignorance lies with other people and until they re-educate themselves into accepting diversity then life for us will remain quite a challenge! Life with Matthew is wonderful and marvellous!

Zoe Wood



Figure 1 Zoe Wood's son Matthew.

2 Support for families

In the UK, support from the NHS and social services tends to focus on diagnosis and the needs of the autistic child, rather than on the family as a whole. The sparse family support that is available tends to be for parents, such as respite breaks for those with a severely affected child.

However, there are many volunteer-run support groups, some of them provided by people who themselves have an autistic child or adult in the family. Additionally, there are groups on social media and email/online bulletin boards that people can subscribe to.

2.1 NAS services

The National Autistic Society (NAS) has assembled [a directory of support services](#) for families with an autistic member. It includes a wide range of service providers as well as services offered by the NAS itself, two of which are outlined below.

EarlyBird

Besides the many services that the NAS offers to autistic people, it also offers some excellent services for parents and families. Parents of younger children (up to age 8) may be able to access an **EarlyBird** or EarlyBird Plus support programme.

EarlyBird is a three-month programme that provides group training sessions for parents with individual home visits. Video feedback is used to help parents apply what they learn as they work with their child in the familiar home setting.



Figure 2 Photos of an EarlyBird session, each featuring parent and child with an EarlyBird trainer who is recording the session.

EarlyBird programmes are run by trained and licensed professionals with the aim of:

- supporting parents in the period between diagnosis and school placement
- empowering parents to facilitate their child's communication skills
- supporting parents to deal resourcefully and positively with their child's behaviour, including more challenging aspects.

EarlyBird Plus is an enhanced form of the service that invites a professional who works with the child (such as a teacher at school) to attend the sessions, so that the child receives consistent support.

Evaluations of both EarlyBird and EarlyBird Plus programmes are positive (Stevens and Shields, 2013). Parents who have participated show reduced stress, more positive perceptions of their children and enhanced communication with them.

The two EarlyBird services are here:

<http://www.autism.org.uk/earlybird>

Parent to Parent Service

'I cannot thank the volunteer I spoke to enough. For the first time as a parent I felt understood. I have felt so isolated for such a long time'.

Anonymous comment from a parent (NAS)

The NAS also offers a telephone service for parents seeking advice, support or just someone to share things with. The **Parent to Parent Service** gives parents a chance to talk to other parents of children on the spectrum, trained to provide this support. This service has proved a popular and effective way of reducing the isolation that parents often feel. The service is here:

<http://www.autism.org.uk/services/helplines/parent-to-parent.aspx>

2.2 Problems in accessing support

A big problem for many parents is finding out what support is available and how to access it. With so much information available online, this might seem surprising. But not everyone has the time, money or skills to seek the help that they need, and there is also the difficulty of deciding which of the many services offered are reputable and risk-free. These difficulties may be particularly salient in ethnic minority communities, accentuated by cultural reservations about using the forms of support that are offered, as Dr Prithvi Perepa explains in these video clips:

Video content is not available in this format.

Yet Prithvi also emphasises that different cultural attitudes to autism may help ethnic families to view autism positively and to seek the support they need within their own community:

Video content is not available in this format.

3 Education

Decisions about nursery and school often pose huge challenges for autistic children and their families. Ensuring that an autistic child is in the right environment is further complicated by the fact that a substantial number of children arrive at school with no diagnosis – their difficulties are first picked up by a teacher. Asperger syndrome or high-functioning autism may only become apparent in the teenage years.

Even if the diagnosis is known, teachers with more able autistic pupils in their class may not be able to reconcile their academic abilities with their communication difficulties and the difficulties experienced in navigating the social world. As Luke Beardon stated:

The fact that I am well-spoken, and my condition isn't obvious worked against me being understood, when my behaviour may have been put down to obstinacy, deviancy, pure eccentricity, or by school peers as being 'mental'.

(Beardon and Edmonds, 2007)

Activity 1 Autism and mainstream school

Allow about 15 minutes

Drawing on your knowledge of autism characteristics outlined in Week 2 and the psychological theories outlined in Week 4, use the space below to note down issues that an autistic child might have in a mainstream school setting. Base your notes on a child who has language skills and is academically able.

Provide your answer...

Discussion

Even a child with good language and academic skills is likely to encounter challenges. The main areas of challenge are likely to include:

- the physical and sensory environment, e.g. sounds, colours and smells to which the child is hypersensitive
- cognition and the curriculum, e.g. the child may have difficulty overriding their focus on a particular topic of interest, or organising their activities through the school day
- the social environment of the school, e.g. the child may find proximity with other children difficult, or may try to make friends and feel excluded.

More detail of these challenges is given in the following section.

3.1 Challenges in educational settings

Now find out more about the challenges explored in the previous activity.

Physical and sensory environment

Classrooms in the western world are typically busy, colourful and information-rich, all of which may overload the senses of an autistic child. Bright colours, patterns, bright lighting, movement and the chatter of other pupils may distract or confuse them, as can examples of work displayed around the room.

Relating this also to the psychological theories encountered in Week 4, a child's excessive attention to detail may mean that they are not clear what needs their focus and attention.

Cognition and the curriculum

An autistic child may have an especially uneven profile of academic strengths and weaknesses, coupled with a strong preference for particular areas of interest. Getting any child to engage with areas of the curriculum that they don't like can be difficult, but in the case of an autistic child, it may be necessary to adapt the curriculum. Executive function issues may affect many areas of school life: getting ready for school, organising the materials needed for a lesson, knowing how to start a task and determining when it is finished, and navigating around the school from one classroom to another. A planner detailing the order of activities during the day may be helpful.

Theory of mind difficulties may make more abstract areas of the curriculum, such as reading or creative writing, a particular challenge to the autistic student. For instance, a child may have difficulty imagining the emotions or actions of the characters. The empathising-systemising model (Week 4) suggests that autistic children are likely to be drawn to systematic subjects like science and mathematics, although this is undoubtedly an oversimplification. Some autistic children particularly enjoy creative subjects such as drama and music, where emotional understanding and expression is called for.

Theory of mind difficulties may also mean that the autistic pupil may not understand instructions or takes them literally, leading to accusations of being cheeky or disobedient. For instance, an instruction phrased as 'Would you like to turn to page 20' may not be followed, because the pupil doesn't realise this is a command rather than a question with optional answers ('Yes, I would like to', or 'No, I would not like to').

Parts of instructions or group discussions may be missed due to slower processing of verbal information. Even more able autistic students benefit from verbal communication being supplemented by written or pictorial information.

Finally, the 21st century curriculum also includes areas such as physical, emotional and sexual health, and understanding relationships. These may need to be presented in a more concrete and explicit way so that the implications and consequences are clear to the autistic young person.

The social environment

Unstructured periods such as breaks and mealtimes may be dreaded by the autistic student, because their lack of social awareness and social motivation distances them from the games and conversations of the other pupils. They find it difficult to join in because of all the 'unspoken' rules and the (seemingly to them) invisible processes by which others communicate.

It is also common for autistic students to be teased by other children, either due to their 'weird' behaviour, the way they speak or because social naivety causes them to misunderstand something. This teasing can very easily escalate into overt and covert bullying, involving name-calling, physical violence or social isolation. Another way that bullying can manifest is by manipulation, when an autistic pupil is coerced by another pupil into breaking a rule or hurting someone.

Surveys suggest that at least 40 per cent of autistic children have experienced bullying, and studies have shown that significantly more are bullied than are children with other special educational needs or neurotypical children (Humphrey and Symes, 2010). As David Hawker notes:

They called me the 'sixth form punch bag' as I was probably about the only kid who got bullied in sixth form (A-levels).

(Sainsbury, 2000, p. 72)

Bullying can result in low self-esteem, mental health problems and poor academic performance. Melanie said that her son Louis left mainstream school at 16 because of the bullying and could not face further education. However, some young people find the resilience to cope with bullying and emerge stronger as a result. Alex talked about his experiences of bullying in Week 2. Here he maintains that his experience of mainstream school was positive, despite what happened to him.

Video content is not available in this format.

4 Educational support and choices: the mainstream and other options

One of the greatest challenges that parents face is to secure appropriate support and the right context for their child's education. In countries such as the UK and the US, a framework is in place for this. But parents' experience of negotiating the framework is not always positive and the range of educational choices varies widely from one place and community to another. Parents may also find that the choice they have made – for instance, for their child to go to a mainstream school – does not work out, leading them to change their child's schooling arrangements.

4.1 Educational plans and statements

To ensure that an autistic child has appropriate support for their education, it is important that their needs are fully understood and documented at the outset. This may require, in England, an **Education and Health Care Plan (EHCP)**, in Scotland a **Coordinated Support Plan (CSP)**, or in Wales or Northern Ireland a **statement of Special Educational Needs (SEN)**. These are legal documents drawn up by the local authority to specify the additional support needs of the child, objectives for them to achieve and the help that they need in order to achieve those objectives. However, some parents report a considerable battle to obtain the relevant statement for their child. Moreover, as in Melanie's case, they may find that additional funding allocated to the school for their own child's support is absorbed into a pool of resources for the support of a number of children:

Louis's 11K was put in the pool to provide teaching assistants (TAs) generally.
As a result he got no one-to-one support.
(Melanie, 2017, pers. comm.)

Another problem is that not all autistic children will receive a plan or statement, as their needs are not considered severe enough. In these cases, parents may find themselves trying to persuade the mainstream school that support is necessary:

In the case of my daughter, who was aged 13 at the point of diagnosis, she was discharged from CAMHS* after we received the report as if the job was done. It was left to us to liaise with her school about what this meant and what adjustments, if any, were appropriate. Autism was an explanation for behaviour deemed to be 'socially inappropriate' and for insecurities in coping with change, anger management, sensory issues and the otherworldliness described as daydreaming. She had developed coping and masking strategies to disguise her sense of difference and to fit in with her peer group. I was told that she was 'borderline', 'very high functioning' due to her intelligence, vocabulary and imagination. As she didn't present as typically autistic in the way that her elder brother [G] did, there seemed to be an assumption that no additional support was needed.

(N, 2017, pers. comm.)

***CAMHS** stands for Child and Adolescent Mental Health Services. In the UK these are services within the National Health Service that assess and treat young people with emotional, behavioural or mental health difficulties.

4.2 Mainstream and other educational choices

Some mainstream schools have a unit attached that autistic pupils can attend for part of the day. This may be for particular lessons or to provide a safe place during breaks and lunchtimes.

If a child is receiving interventions such as **TEACCH** or **PECS**, then these need to be built into the school day, to provide consistency. Autism units within mainstream schools may not be appropriately resourced for such specialised support. This is easier to deliver if the child attends a **special school**, as these will be geared to using such approaches and will have staff who are trained in them.

Some children's behaviour may require a highly structured environment throughout the day, such that the only option is a **residential school**. Children attending residential schools may return home for some or all weekends, or only during the holidays. Some may not even be able to do this, although their families will visit them. For G, who is now 17 years old, special school has been a positive experience:

G is now 17 with very limited language and attends a special school. He seems happy and well-liked by teachers and peers; he is sociable, affectionate and has a sense of humour. He cannot live independently, but with support is able to dress himself, shower, use the washing machine, dishwasher and help with cooking – he loves food. He bounces like Tigger when we are out and about (drawing attention to himself), but now goes to the gym and enjoys running and swimming.

(N, 2017, pers. comm.)

Places at special schools and residential schools are limited and are only available to those children with an EHCP, CSP or Statement of SEN. In the late 20th century there was a move away from special schools, towards placing as many children as possible in mainstream settings. The emphasis on 'inclusion' reflects the belief that it is better for autistic children to be educated alongside neurotypical children in their community, thus being involved in all the social and academic activities that other children experience.

Sadly, despite the advantages of mainstream school, many autistic children do not feel included, lack friends and may not achieve their academic or vocational potential. As you have learned throughout this module, autism is highly heterogeneous: in education (as with so many other areas of life) a 'one size fits all' approach does not work. It is essential that the individual needs of the child are considered, and that the right education context is found.

4.3 Educational provision in regional and international context

Many parents of autistic children in the UK feel that their choices are limited. However, the range and quality of educational choices is substantial compared with provision in many

other areas of the world, and especially in low income countries. For instance, Ethiopia has a population of nearly 100 million people, of whom more than half are children – yet until recently there have been only two schools for autistic children. These are in the capital city, Addis Ababa, and were founded by two mothers, both of whom have taken important steps in improving support and services for children with autism (Tekola et al., 2016).

Activity 2 Educational provision for autism in your area

Allow about 15 minutes

If you are in the UK, explore the internet to find out about educational provision near to you. You may find it useful to access the NAS Autism Services Directory, which you will find here: <http://www.autism.org.uk/earlybird>

Check which of the following types of provision are available:

- mainstream school with an autism unit
- special school
- residential school.

If you are studying outside the UK, see if you can find out where the nearest autism-friendly school is located.

4.4 Home education

Some parents choose to home-educate their children. They may have tried mainstream and/or special school options, and found both to be unsuitable for their child. Their child may have had bad experiences or failed to progress, or parents may be using interventions such as **Applied Behavioural Analysis (ABA)**, which cannot be readily implemented in school. Receiving formal education at home is often a lot less stressful and anxiety-provoking for the child because it is a familiar environment, and the day can be structured to suit their routines and interests. However, it can be more stressful and exhausting for parent(s), and is financially costly if paid employment has to be given up. Parents may also find it hard to obtain the necessary teaching materials and they may lack sufficient information about what the child should be learning. Parents undertaking homeschooling are not obliged to follow the National Curriculum, and this may benefit the child in the short to medium term, but difficulties may arise if the child ever wants or needs to take formal qualifications such as GCSEs and A-levels. Despite his regrettable experience of bullying, Alex is positive about his formal mainstream education, which has equipped him for university studies. Home education may be the best choice for some children, but it is not an easy option or one that all parents could manage.

In this video clip Arabella, mother of Iris Grace, explains why she took the decision to educate Iris at home:

Video content is not available in this format.

Activity 3 Home education

Allow about 5 minutes

Besides the potential drawbacks of home education just outlined, can you think of another important developmental opportunity that home-educated children are likely to miss out on?

Provide your answer...

Discussion

All home-educated children, whether autistic or not, may lack opportunities for interacting and learning to socialise with other children, an important part of their learning and progression towards adulthood. However, it is possible to join a network of other home-educating parents and participate in organised outings or joint learning sessions. Some parents have even set up groups in their own homes to facilitate their child's interactions. In this video clip Arabella talks about the Little Explorers Activity Club that she runs from home, bringing Iris Grace together with other autistic children for informal learning activities:

Video content is not available in this format.

5 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 6 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

6 Summary

This week you have looked at key challenges facing families when one or more members is autistic. This week's material has outlined the forms of support that are available to families, and touched on the difficulties that some families may have in accessing this support. It has also highlighted the remarkable resilience often present in the face of difficulties, including in multiplex families. One of the biggest challenges for parents is finding the right school or other educational option for their child. The key features of the main educational choices available in the UK were described, and the arguments for and against different options were considered.

You should now be able to:

- appreciate different ways in which family life may be affected when one or more family members is autistic
- understand how challenges for the family and for the individual with autism change over the course of development
- be aware of some of the sources of support available to families in the UK
- appreciate the psychological, academic and social challenges posed by education, and the main choices available in terms of schooling
- understand the rationale for different educational choices, including home education.

Next week focuses on what happens when a young person with autism leaves school and enters adulthood.

Now you can go to Week 7.

Week 7: Adulthood

Introduction

Most of what you have learned so far has focused on children. However, autism is usually a lifelong condition with many core challenges persisting in adulthood – although there is also change and development, just as for any neurotypical person growing up. Some young autistic adults succeed in overcoming multiple challenges and adapt to independent living, and as you saw in Week 5, a small proportion achieve ‘optimal outcomes’, becoming free of their autistic symptoms. For others, serious challenges affecting autonomy and well-being persist. Some people only discover their autism in adulthood, often after years spent struggling with a sense of being different. Across these different groups, several things are clear:

- less is known about how autism affects people in adulthood
- the factors that lead to different outcomes in adulthood are not fully understood
- less help and support is available for adults than for children.

This week discusses what is known about autism during and after the transition to adulthood and in older age. It describes some different life scenarios for autistic adults and the challenges that they may face, for instance in employment and relationships. It outlines some of the provision and support available, but also highlights the many gaps, whether in the UK or worldwide.

Now watch the video in which Dr Ilona Roth introduces this week’s work:

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By the end of this week you should be able to:

- understand problems relating to the transition into adulthood for autistic people
- appreciate factors that may affect outcomes in adult life
- be aware of the range of outcomes that may result for autistic adults
- understand particular challenges in adult life concerning independence, employment, relationships, legal issues and health
- be familiar with forms of support available for adults and their limitations.

1 The transition to adulthood

The transition from childhood to legal adulthood at the age of 18 has been described as ‘falling off a cliff’ because there is generally very little provision for autistic adults. As for any young person, the moment of leaving school marks the loss of a familiar social

network. But whereas most neurotypical 18-year-olds can look forward to making new friends at college or work, those with autism may find themselves isolated again, augmenting the risk of depression and other mental health problems.

In this section we discuss some key considerations within the transition to adulthood.

1.1 The importance of ongoing education

Educational placements stop at 18 or 19. However, because autism can be associated with delays in development, many would benefit from a more extended period of education in a broad range of skills.

Skills learned at school may be lost if there is no post-school placement to reinforce and practise them, and continuing education is needed both for learning daily living skills and enabling autistic people to gain employment, where possible. Social and communication skills can continue developing for many years. However, further education colleges may not have the resources to support young people with autism, and specialist colleges are sparse.

1.2 Higher education and beyond

Many children with good intellectual skills do well in public examinations such as the UK system of GCSEs and A-levels, and some go on to university. Students within all four countries of the UK can obtain an allowance for relevant ‘non-medical’ support, such as a note-taker in lectures and a mentor to assist coping. However, such funding does not continue after graduation.

The young person may be unable to negotiate the complexities of applying for jobs or attending interviews. Even claiming out-of-work benefits may be impossible: forms are often written in complex bureaucratic language that anyone can find a challenge. So even young people with qualifications can find themselves returning to live with their parents or struggling on their own. This may contribute to the high level of mental health issues noted earlier.

1.3 Education, Health and Care Plan

The new Education, Health and Care Plan (EHCP) introduced in England in 2014 covers the additional support needs for children and young people up to the age of 25. The EHCP can fund a placement at a specialist college (if available), and can offer a personal budget so that a young person or their designated carer can decide what support to buy.

However, according to an NAS survey (Moore, 2016), a majority of parents remain dissatisfied with the new system, especially in relation to health and social care. It is unclear how effective the EHCP system has been in securing services for young adults.

At present the Coordinated Support Plan (CSP) used in Scotland, and statements of Special Educational Need (SEN) used in Northern Ireland and Wales do not provide the continuity into adulthood that the EHCP is designed to provide; families have to negotiate support after their children leave school.

2 Living arrangements

In this section you will look at living arrangements for young people with autism.

2.1 Residential support

The parents who started the National Autistic Society (NAS) in the 1960s and set up the first schools for children with autism all too soon found themselves addressing provision for their adult offspring to experience the kind of structured environment that would enable them to achieve their potential. Previously, offspring such as theirs may have been committed to long-term institutions for those most unfortunately described at the time as 'feeble-minded'.

This led some parents to purchase a property that could become a residential home for their adult offspring: Somerset Court, near Burnham-on-Sea, was established in the early 1970s. Subsequently the NAS has set up some other small residential homes around the country. Each aims to help residents augment their social and communication skills; learn some everyday life skills such as cleaning, shopping and cooking; and gain in confidence, with the support of specialist staff. Approaches such as TEACCH, discussed in Week 5, are used to create a structured environment. Residents may attend a local college for day and evening classes, or learn some vocational skills. Somerset Court has its own onsite resource centre.

Other local autism charities have similar facilities, with places funded by local authorities. Another option is to attend a local daycare centre, although these may not be autism-specific. A person must have been assessed by social services, and have had funding agreed, in order to gain access to such services.

2.2 Support for independence

In some areas of the UK, independent living is facilitated by access to funded support. Some adults obtain direct funding for a part-time support worker to help with areas of daily living where they have difficulty, such as self-care or dealing with officialdom. Some NAS adult services are directed towards more able adults, including small social groups that aim to help with the continuing development of social skills. The success of such arrangements depends on the individual case. Melanie's son Louis lives with his father, with frequent visits and input from Melanie herself, and support from other services:

Louis is on Direct Payments and pays helpers to take him out so this is good. The social worker changes every six or 12 months so there is no continuity and no help to get him moved into independent living. He finally has a local psychiatrist and is on heavy medication to calm him down. [My hope for the future is for Louis to be] independent and safe from eviction or life on the streets after I and his father die. He'll never work. I pray the welfare state will always exist to support him.

(Melanie, 2017, pers. comm.)

Alex lives at home while studying for a degree and working part-time, although he hopes to move into his own place eventually. In this clip he talks about his mentor and also the social group he attends:

Video content is not available in this format.

2.3 Adult support in international perspective

As outlined in earlier weeks, services for autistic children in many lower and middle income countries (LMICs) are very sparse. The gap is even greater for adults, as illustrated by a recent interview study of South African professionals and parents (Meiring et al., 2016). In some ways the fears about transition expressed by South African parents mirror those of parents like Melanie, quoted earlier. But the situation is more extreme, as these quotes from parents illustrate:

'It's a very, very scary thought, it's a very sad situation, to be very honest, there is nobody, after us [parents] there is really nobody ...'

'No I don't know of any [transition arrangements] ... I have 'googled', I have looked, it's only overseas where I see there is so much support systems ...'

(Meiring et al., 2016)

3 Adult outcomes

Adult outcomes is the term for what happens to people with autism once they transition into adulthood. One reason that relatively little is known about outcomes is that autism was only identified in the 1940s, and it took several decades for the diagnosis to become well-known.

So until recently there have been relatively few adults on whom to base outcome studies. This situation is changing, and an increasing number of longitudinal studies have tracked the progress of children with autism into adulthood. Key findings from 25 such studies have been assembled and evaluated by Magiati et al. (2014).

3.1 Cognition, language and adaptive functioning

The researchers reported that cognitive function (for instance as measured by IQ scores) remains stable for many adults on the autism spectrum.

However, there is much individual variation, with evidence that IQ improves for some individuals and declines for others. Language function tends to improve in adulthood, but in most cases significant difficulties remain. **Adaptive functioning** means an individual's capacity to deal with everyday tasks such as dressing and washing oneself, and communicating personal needs.

On the whole, measures of both adaptive functioning and the severity of core autism symptoms show improvements, but again there are individual variations.

3.2 Social life, independence and mental health

The most consistently negative results from Magiati's report concern social life and independence in adults on the spectrum. More than half of participants remained fully or largely dependent on parents or carers in adulthood, and needed significant support for education and living arrangements. Few have friendships, romantic relationships or employment. Correspondingly, the NAS estimates that only 16 per cent of adults in the UK are employed (National Autistic Society, 2016).

More than half of autistic adults are likely to have some mental health difficulties, most commonly depression and anxiety. It is not clear to what extent mental health problems are a feature linked to autism itself, or a consequence of social isolation and society's response to autism. The need to overcome rigid routines, make decisions or adapt to new circumstances in order to engage with the world could provoke extreme anxiety. Behaving and thinking 'differently' and being awkward around others could lead to the difficulty in forming relationships and obtaining employment.

In general, the **quality of life** experienced by adults on the spectrum is lower than for neurotypical adults (van Heijst and Geurts, 2015).

3.3 What factors influence outcomes?

IQ and language ability play a role in shaping adult outcomes. In general, those with a higher IQ and better language skills are likely to have more favourable outcomes in

adulthood. But the pattern is very mixed: the quality of support available and the individual's own resilience are likely to play a role in adult well-being, and as we shall see, what counts as a favourable outcome should be judged in relation to the individual, rather than to some absolute standard. A successful individual outcome doesn't necessarily mean that the person has 'outgrown' their autism or that they are living independently, with a job and so on.

4 Outcomes across the spectrum

The extent to which autistic people are capable of a ‘standard’ adult life varies greatly. In general, those more profoundly affected are more likely to need care and support, either at home or in a residential home. However, this group may also include high-functioning adults, who experience disabling levels of anxiety, or find that adaptive functioning skills – such as dressing, preparing a meal for themselves or paying bills – are too challenging. On the other hand a substantial number of adults do live independently of their parents or other forms of support. This group undoubtedly includes many people whose autism is undiagnosed.

Finally, a small proportion of those on the spectrum do appear to lose their autistic symptoms altogether, achieving what have been termed optimal outcomes. This section considers a range of outcomes, incorporating individual life stories.

4.1 Timothy Baron

In earlier weeks, Michael Baron talked about his profoundly autistic son, Timothy, one of the first children to be diagnosed in the UK. Timothy is in his 60s now. Despite remaining in residential care for most of his life, Michael sees real progress in how Timothy experiences and engages with the world:

What I think when I see him, and I saw him yesterday, is that the ... rage and the disturbance that was the hallmark of Timothy at the age of four ... that's all sort of fallen away. ... He isn't an angry middle-aged man. And in a way I think that the autism in a sense has fallen away and you are left with, in his case, a learning disabled, middle-aged man ...

It's just a theory that ... he is not so, as it were, classically autistic as he used to be. ... He is calmer and he is more sociable, can live in a community, can do things that he wouldn't have been able to do before and he is not so disabled by his autism as he was.

(Baron and Roth, 2017)

Michael is saying that the outcome for Timothy is successful compared with other possible eventualities for him as a profoundly affected person. This is a judgement in individual terms, rather than in relation to society’s norms.

4.2 Donald Triplett

In the 1940s, Donald Triplett was one of the small group of children from whom Kanner first formulated his ideas about autism. Among Kanner’s case notes at the time is this quote from Donald’s mother:

Another of his recent hobbies is with old issues of Time magazine. He found a copy of the first issue of March 3, 1923, and has attempted to make a list of the dates of publication of each issue since that time. So far he has gotten to

April 1934. He has figured the number of issues in a volume and similar nonsense.

(Kanner, 1943, p. 222)

You may note a hint of exasperation at Donald's unusual special interest. His mother had also concluded that he was mentally ill, and on the advice of psychiatrists, she and her husband had Donald committed to an institution. But they regretted their decision and brought him home again after a year. When he was growing up, Donald was described as socially aloof and eccentric, but with a number of savant skills, such as his exceptional memory for numbers. Despite his difficulties, he sustained employment in a bank, and learned to drive, play golf and to travel independently.

Donald is in his eighties now, enjoys his life and remains a valued and cherished member of his community in Forest, Mississippi. Factors that have clearly made a big difference to this outcome are his parents' positivity, their ability to ensure a secure future for him and the positive social support he has received from the community. Although he remains a loner, he meets others to play golf, and participates in church and other local activities (Donvan and Zucker, 2010).

4.3 Wenn Lawson

Donald Triplett's story is not just about the support of others, but also his own positivity and resilience in the face of difficulties. These attributes feature strongly in the life story of Wenn Lawson.

In an interview recorded for The Open University in 2011, Wenn described his difficult relationship with his parents, misdiagnosis with schizophrenia aged 17, troubled marriage and loss of a child in a car accident. But he also talked of his success as an academic, writer and autism advocate, some of which he attributed to the love and support he found with another partner after divorce. Wenn studied psychology with The Open University, and considered distance study to be ideally suited to people on the autistic spectrum:

[The OU] enables us to not have to mix with lots other people who might actually take away from our ability to learn. The fact that you can be in a classroom where you have got people clicking pens, turning pages, all the sensory overwhelming stuff that comes from just being with lots of people, closes me down. Whereas distance education, like the Open University courses, I can study at home, I can set up my study area, I can organise my studies, all the materials are posted out to me, I've got time to process the whole event of distance education in a much better way than I can if I had to go to a typical university.

(Lawson and Roth, 2011)

4.4 Optimal outcomes

Longitudinal work by a few research groups suggests that a small group of children with an autism spectrum diagnosis completely lose the symptoms consistent with this diagnosis, though they may retain some subtle symptoms similar to ADHD (Suh et al., 2016). Research into what factors might promote this outcome is still at an early

stage. Deborah Fein, a leading researcher in this field, suggests that a high proportion of the optimal outcomes group have received intensive early ABA intervention (see Week 5), but also speculates that biological factors may differentiate the group from others on the autism spectrum.

This kind of outcome is not common, and becoming free of autism should not be considered the only good outcome. Some feel that their autism is integral to their identity and would not wish to lose it. And as the lives of Timothy Baron, Donald Triplett and Wenn Lawson all show, positive outcomes in adulthood should be evaluated in relation to the individual.

5 Addressing challenges in adult life: employment and relationships

Sections 5 and 6 consider the major challenges faced by many adults on the spectrum, whatever their setting.

5.1 Employment

Activity 1 Challenges at work

Allow about 15 minutes

Imagine that someone on the autism spectrum has started a new job based at a company not far from their home. Bearing in mind what you have learned about autism up to now, use the space below to identify two kinds of difficulties that this person may find especially challenging in the work environment, and suggest a helpful adaptation that an employer could make for each one. You may find it useful to refer back to Week 6, where Activity 1 called for comparable reflections relating to education.

- 1.
- 2.

Discussion

You may have identified some of the following challenges:

Physical and sensory environment

The autistic employee may find the noise, smells and visual stimuli of the office disturbing, especially if it is open plan.

An employer could help by providing the employee with a secluded work area, where these stimuli are minimised.

The work day

Employees may be expected to carry out their work in a particular sequence and at a particular rate, and to respond flexibly if new priorities unexpectedly crop up. Such organisational matters may pose great challenges for autistic employees. For instance, an autistic employee may tend to focus in great detail on one task to the exclusion of others, and may have great difficulties in switching to something else as required.

An employer could help by providing as much flexibility as possible, and by employing the autistic person's strengths, e.g. by allocating work that needs to be carried out with extra precision and care, or giving responsibility in areas of work requiring particular numerical or IT skills.

Communication

Autistic employees may struggle to understand or carry out instructions if these are implicit or not delivered clearly enough.

Employers and other staff can help by always choosing clear, direct language and avoiding metaphors.

Social context

The autistic employee may be disturbed by close proximity to others (e.g. in an open plan space), or by the expectation to socialise in lunch breaks or after work.

As for sensory stimuli, an employer could help by providing a secluded work area. He/she could also seek the employee's permission to explain their needs to other employees.

Other measures that may help in the work setting include:

- allowing part-time working and/or 'mental health days' if the person becomes too stressed by having to interact with colleagues
- permitting a mentor/advocate to act as an intermediary between the autistic person and their colleagues or managers.

5.2 Support for employment

The NAS has some support centres across the UK and an outreach team that aims to assist with preparing for work, for instance by building on social and practical skills, confidence and experience, as well as CV writing. However, because it is a charity, such support centres are few, and many people do not have access to them. The NAS also offers advice and training for employers on understanding autism and how to manage people with autism.

There are also commercial companies that help autistic people into meaningful and productive employment. At Specialisterne, which started in Denmark and now operates in 11 different countries (although not the UK), employees are found work as business consultants on tasks such as software testing, programming and data entry for the public and private sectors. Auticon has bases in London and Munich, and works on similar principles. Their employees are all on the autism spectrum and work as consultants for various clients, with a job coach who gets to know the consultant and their capabilities, assesses the work environment for any reasonable adjustments that could be made, acts as a mediator and may initially help the autistic person with travelling to and from the job.

Autistic people have many skills to offer in the workplace, and simple respect and friendship from fellow employees may be as important to well-being as specific support measures. In this clip Alex talks about his very positive experiences of working part-time in a bookmakers:

Video content is not available in this format.

5.3 Relationships

The lives of autistic adults can follow a neurotypical pattern such as gaining employment, getting married and having children. Some may make great efforts to behave in a way that means that, at most, they are considered a bit eccentric. There is growing evidence that

females, in particular, may seek ways to mask their autism in order to fit in. Perhaps only their close family sees their struggles and the impact of maintaining this façade.

Autistic adults may find relationships difficult, on many different levels, and many do not enter into intimate relationships. In his account of Temple Grandin, the writer and neurologist Oliver Sacks wrote that Temple had never dated or been in a relationship:

She found such interactions completely baffling, and too complex to deal with.
'Have you cared for somebody else?' I asked her. She hesitated for a moment before answering, 'I think lots of times there are things that are missing from my life'.

(Sacks, 1995, p. 122)

Many feel lonely and would dearly like to have an intimate relationship with another adult, but lack the social skills or social understanding to know how to even start the process, or to know when it is appropriate to take things to a deeper level from 'friendship'. If a relationship does blossom, the partner/spouse can sometimes find life frustrating because of the autistic person's lack of understanding of their emotions:

Occasionally things do go wrong. Having explained carefully, calmly and rationally why I feel upset, I will check that Chris has understood and when he replies 'Not really', there is the old temptation to find something expendable in the kitchen.

(Slater-Walker and Slater-Walker, 2002, p. 72)

Activity 2 Thinking about relationships

Allow about 15 minutes

What aspects of autism might pose challenges in relationships? Think of this in relation to parents' relationships with their adult offspring, or couples where one or both is autistic. Use the space below to answer the following prompts:

1. Draw on what you have learned so far to suggest three challenges.
2. Note two autistic characteristics that could be beneficial in a relationship .

Provide your answer...

Discussion

1. You may have thought of some or all of the following:
 - o Parents may find it frustrating or tiring to provide support for tasks that most neurotypical adults can cope with, such as completing forms or applying for jobs.
 - o Some attributes, such as literal understanding and speaking, or fixations on spinning objects or Thomas the Tank Engine, which may be endearing or amusing in a child, may be harder to tolerate or understand in an adult.
 - o The autistic person may be unaware of the stress that caring for them can cause – often alongside other stressors, such as caring for elderly parents, grandchildren or a spouse/partner.

- Social situations like parties or family get-togethers may be difficult. The autistic person may come across as odd or rude in social settings, leading to feelings of awkwardness in their parents or partner.
 - Autistic people may find it very hard to deal effectively with the usual conflicts and disagreements that crop up in a relationship. Social communication difficulties and a lack of emotional insight may impede resolving even small problems and may affect the relationship more than they should.
 - An autistic partner who can't anticipate their loved one's thoughts, interests and motivations may feel bemused or even annoyed by their actions.
2. The positive qualities that autistic people may bring to relationships include their loyalty, commitment and honesty. Close attention to detail could be trying in some circumstances, but could be helpful, for example, in planning a holiday or sticking to a budget. It is important not to think exclusively in terms of challenges.

6 Addressing challenges in adult life: legal issues, health and ageing

An autistic person may come into contact with the criminal justice system, either as a victim or witness of crime or as a suspect.

6.1 The criminal justice system

There are several reasons why autistic people may be especially vulnerable to crime. For instance, unusual behavior in a public place may, sadly, attract physical bullying or other hate crime. Naivety about other people's motives may make the autistic person especially vulnerable to fraud. It may even result in the autistic person being drawn into committing a crime. Anecdotally, an autistic person has been caught as the perpetrator in several recent cases of computer hacking, while other more devious members of a hacking group have got away.

Autistic people are no more likely to be in prison than any other section of the population (King and Murphy, 2014). However, as we have seen, they may have been manipulated into engaging in criminal acts, or have missed social cues that would have otherwise prevented them from acting this way. It is also possible that some are wrongfully imprisoned because difficulty in understanding police procedure or questioning has led them to admit to crimes they did not commit.

All of these situations require that police officers and court personnel are aware of a person's autism and follow correct procedures. Adjustments made by the police and courts can include:

- an interview location where the lighting, chair coverings or officer's clothes can be adjusted so as not to cause sensory overload
- presence of a parent, carer, advocate or support person
- a registered intermediary to advise the police or court on how to phrase questions so they are fully understood
- in court, the autistic person may be able to use the live video link or to have their interviews and cross-examinations recorded.

As with other aspects of public life, the NAS is working towards awarding **accreditation** to organisations that demonstrate a commitment to understanding autism, and making appropriate accommodations. The UK Ministry of Justice is encouraging prisons and young offender institutions to become accredited. The NAS also offers a free guide for legal professionals and police officers who find themselves working with autistic people.

6.2 Health and ageing

Autistic adults may be susceptible to particular health problems and also to accidents for a range of reasons.

As you have learned in earlier weeks, epilepsy, depression and other health problems are 'comorbid' with autism. In addition, narrow food preferences may lead to an unhealthy

diet, which could put the individual at risk of obesity and heart problems. Some autistic people are relatively insensitive to pain, which means that serious health problems such as a broken bone go unreported. In emergency situations (e.g. on admission to hospital), a person with autism may be unable to make decisions or insist on their treatment rights, and in rehabilitation, they may not appreciate the importance of following medical guidance.

Any of these factors could potentially affect life expectancy in autism, and there is some evidence for raised mortality (Howlin and Moss, 2012), although more work is needed.

Research is also lacking into how autism impacts conditions of older adulthood such as dementia, or whether older autistic adults have unique health needs. As more and more diagnosed adults are becoming elderly, this is an area that needs urgent attention. For instance, is dementia more common than in the general population, or might autism provide a protective function?

7 The Autism Act and related legislation

A landmark piece of legislation in England was the Autism Act of 2009, which came out of an NAS campaign to highlight the problems faced by autistic adults. It required all local authorities to develop an autism strategy to provide relevant services, from the authority themselves and from other bodies such as NHS trusts, in order to meet the needs of autistic adults, including:

- clear and consistent pathways to diagnosis for adults
- identifying adults in the area already diagnosed as autistic and assessing their needs
- planning for children transitioning to adult services
- training for staff providing services
- providing help into employment, including developing skills and overcoming barriers which may prevent the person accessing job opportunities.

Building on the first national strategy 'Fulfilling and Rewarding Lives', an updated strategy called 'Think Autism' was introduced in 2014, with some government money to be used for projects developing local services. There is also a commitment to training for GPs and other healthcare professionals, as well as Disability Employment Advisors at Jobcentres.

The Northern Ireland Assembly passed an Autism Act in 2011, which has a similar focus to the Act in England. Scotland has an autism strategy that covers both children and adults, with aims including supporting autistic people through the many challenges that they might face in their lives, improving people's quality of life and supporting them into employment where appropriate. Although Wales has an autism strategy, it is not backed by legislation. There are gaps in service provision and diagnosis for adults can take up to seven years in Wales. At the time of writing, the NAS is campaigning for an Autism Act in Wales that is similar to the one in England.

Yet some bodies, such as the Shirley Foundation, have been very critical of the lack of progress made UK-wide in recognition and support for autism since this legislation came into being, and recommend further research into good practice, what is most effective and where money should be spent (Iemmi et al., 2017).

8 This week's quiz

Check what you've learned this week by taking the end-of-week quiz.

[Week 7 quiz](#)

Open the quiz in a new window or tab then return here once you've finished it.

9 Summary

This week has painted a sometimes sombre picture of the many difficulties and challenges that confront autistic adults in all aspects of their lives. Yet we have also highlighted positive outcomes, individual resilience and the benefits that autistic characteristics may offer at work and in relationships. We will end on a similarly optimistic note with a comment from Alex about his achievements so far and hopes for the future:

Video content is not available in this format.

You should now be able to:

- understand problems relating to the transition into adulthood for autistic people
- appreciate factors that may affect outcomes in adult life
- be aware of the range of outcomes that may result for autistic adults
- understand particular challenges in adult life concerning independence, employment, relationships, legal issues and health
- be familiar with forms of support available for adults and their limitations.

Now you can go to Week 8, the final week of the course.

Week 8: Reflecting back, looking forward

Introduction

This week you will think about what you have learned so far, where we are today with our understanding of autism and what the future might hold. Attitudes to and provision for autism are changing, although at different rates across the globe. You will reflect on the changes in countries such as the UK, and consider priorities and challenges for the future, including for lower and middle income countries (LMICs), with a special focus on Ethiopia.

Now watch the video in which Dr Ilona Roth introduces this week's work:

Video content is not available in this format.

By the end of this week you should be able to:

- evaluate how your own knowledge and understanding has increased while studying this course
- appreciate both shared problems and differences in the lived experience and needs of autistic people
- discuss trends and priorities in autism research and support
- identify wider societal issues that affect the lives of those with autism and their families
- understand some of the priorities for autism in low resource settings.

1 Autism: what have you learned?

Now try the following activity.

Activity 1 Reflect on what you have learned

Allow about 10 minutes

Use the space below to note key things that you have learned about autism so far in the course. You might want to check back to the notes you made for the same exercise in Week 1, Activity 1. In what ways has your understanding changed most? What do you consider to be the most important insights you have gained?

Display of content entered previously

Provide your answer...

Discussion

Here are some key points you may have noted:

Understanding autism should have helped you to gain a wider knowledge of what autism is, and how it affects children and adults across the lifespan. You have learned how the concept of autism has changed, and with it the tools used to diagnose it. You have considered how the impact and experience of autism varies between individuals, and how perceptions of autism may be affected by cultural context. You have looked at explanations of the causes of autism, and at the benefits and drawbacks of different approaches to intervention and support. You have considered how autism may affect families, and looked at the particular challenges of adulthood. You have also learned that autistic people have strengths and skills, and need scope to fulfil their potential.

Now we will reflect further on some key themes, ongoing issues and implications for the future.

2 The autism spectrum in the 21st century

As you learned in Week 1, knowledge about autism has come a long way in the last 8 decades – including recognition that it encompasses a great deal of diversity. The DSM-IV diagnostic criteria attempted to encompass this diversity by distinguishing differentiating sub-types such as childhood autism and Asperger syndrome (see Week 3, Section 2.2), but this proved problematic because the overlapping symptoms meant that diagnosis could not reliably differentiate between these categories.

The recent DSM-5 diagnostic criteria define autism as a single spectrum but also allow an individual profile to be specified for each person diagnosed. The ICD-11 criteria published in 2018 mirror DSM-5 in many respects, yet do recognise sub-types, differentiating autism with and without intellectual disability. Debate continues about the best way to capture both the shared features and the diversity of autism. Some different perspectives that bear on this issue are discussed in the next section.

2.1 ‘When you’ve met one autistic person, you’ve met one autistic person’

The above phrase is used by some autistic people and those who know them to emphasise that each autistic person is uniquely different and needs to be understood individually – within the broad framework of the social, communication and non-social differences that are implied by an autism diagnosis.

As you have seen throughout this course, first-hand accounts from autistic people provide important insights into the ways autistic individuals see the world, although inevitably these are limited to those who are able to articulate their **self-awareness** and describe their experiences. These accounts enable autistic people to voice their feelings and ideas, highlighting the diversity of autism from an inside perspective and qualifying insights from research and clinical practice. However, the individuality of these accounts means that no single personal account can represent everyone on the spectrum. For instance, Temple Grandin describes that she ‘thinks in pictures’ (Grandin, 1996); this may be true for others on the spectrum, but it is not universal. Wenn Lawson has described his thought processes as more verbally based (Lawson and Roth, 2011).

2.2 Neurodiversity

The relationship between the autism spectrum and the rest of the population is one with important social and ethical implications. Traditionally, autism was seen as akin to a medical problem – diagnosed by medical professionals and regarded as a disorder and/or disability, with deficits that impair the individual’s functioning and depart from the ‘norm’. Historically, this was the perspective most strongly associated with the idea of a ‘treatment’ or ‘cure’ aimed at returning the individual to ‘normality’.

Nowadays, many individuals with autism and their families prefer to think of autism as a difference from neurotypicality (and note the use of this term in preference to ‘normality’).

Some, including members of the **Autism Rights Movement**, altogether reject the concept of autism as a disability, arguing that being autistic is simply a valid alternative to neurotypicality, and something to be celebrated.

Here Arabella reflects on coming to accept and celebrate Iris Grace's unique qualities

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An associated perspective first introduced in Week 1 is 'neurodiversity'. This extends the 'difference not disorder' perspective to include individuals with a range of cognitive differences besides autism, such as dyslexia and ADHD. Neurodiversity advocates argue that these conditions arise due to natural genetic variation and are not '**pathological**' (medically disordered), but should be recognised as a social category like ethnicity or sexual orientation. They suggest that it is society that needs to change, to accept autistic people for who they are and to accommodate their behaviours.

Those in the 'difference not disorder' lobby are making valuable contributions to changing perceptions about autism. However, their views are not universally shared. In particular, some families where there is a profoundly affected autistic individual may feel that while the neurodiversity view is appropriate for high-functioning individuals who lead relatively independent lives, it fails to acknowledge the distress, suffering and disability of those such as their own family member.

2.3 One autism or several autisms?

In a recent interview, Michael Baron, father of Timothy, echoed the concern that society's current image of 'what autism is' downplays or overlooks the difficulties of people like Timothy:

On the one hand the increased awareness [of autism] is a good thing and can only make things better. And on the other hand I'm no longer sure that the label is right for all the people who say 'oh I've just been diagnosed' ... I think the situation has become very fragmented, very confused. The language is very difficult and in a sense I don't recognise it. And so when I look back the parents I knew ... of – let's use that awful word – handicapped children, they were children who were made dependent by their disorder and over the years they have changed maybe from being the majority to being ... not so big a majority, maybe in fact a minority now. So it has changed enormously.

(Baron and Roth, 2017).

Michael Baron's view is that the time may have come to reconsider – again – the idea of a unified autism condition. Interestingly this is an ongoing topic of discussion among clinicians (Boustead, 2015), and fits with suggestions by some geneticists. As outlined in Week 4, genetic studies have shown that DNA variants on a large number of genes may be involved – besides some rare cases, it is a polygenic condition. Moreover, autistic people seem to have different combinations of candidate genes, meaning that it is a heterogeneous condition. On the face of it, this genetic variation fits well with the idea of a spectrum of heterogeneity and individuality at the level of symptoms and behavior.

Yet some experts maintain that the future lies in fragmenting autism into different disorders or conditions. These would be defined in terms of which genes are affected and

how these relate to distinctive patterns of physical characteristics such as digestive problems and traits such as intellectual disability (Deweerdt, 2014). Creating genetically differentiated autism sub-groups has made it possible to link some families whose children have characteristics in common, enabling the families to share information on what interventions have worked for their children, to provide guidance for teachers, and to inform research. However, given the vast range of possible genetic variants that have been identified in autism, and the fact that some of these occur in conditions other than autism, it may only be possible to group a small proportion of autistic people in this way. The debate about whether and how autism can be subdivided is ongoing.

However we think of the autism spectrum, it is clear that some autistic individuals manage and even thrive without support, while others need as much help as they can get. The challenge to us all is to strike the right balance between respecting autistic people's right to autonomy and self-determination, while providing support wherever and whenever it is needed, including in the areas where even quite able people struggle. Autistic individuals should have as much input as they can into decisions about their care and support. This **person-centred planning (PCP)** enables people to maintain dignity, while also helping to identify the accommodations they may need to function at their best.

3 Future directions for autism research

In Week 1 it was argued that some of the most reliable information about autism comes from properly conducted research studies. But what questions should such research focus upon? In the last few decades, funding agencies have injected huge sums of money into research into explaining autism, including psychological, neurobiological and genetic factors. But many, especially those in the autism community and their carers, believe that other issues impinge more directly on their lives and well-being, and should take higher priority in terms of funding.

3.1 What are the priorities?

In the following activity you will explore the priorities for the future directions in autism research.

Activity 2 How should funding be allocated?

Allow about 20 minutes

Drawing on the knowledge you have gained throughout the course, use the space below to list five fields in which you think funding for research would be most worthwhile.

Provide your answer...

Discussion

In 2016, a UK survey by the research charity Autistica, in collaboration with the NAS, Research Autism and others, asked participants to list their top priorities for research funding (Autistica, 2016). The 1213 respondents included individuals with autism (23%), family members and caregivers (52%), and clinicians and other professionals (25%). The 25 most frequently listed choices were compiled and put to another panel, comprised of equal numbers of people on the spectrum, parents and carers, and clinicians and professionals. The top ten selected areas were as follows:

- Which interventions improve mental health or reduce mental health problems in people with autism? How should mental health interventions be adapted for the needs of people with autism?
- Which interventions are effective in the development of communication/language skills in autism?
- What are the most effective ways to support/provide social care for autistic adults?
- Which interventions reduce anxiety in autistic people?
- Which environments/supports are most appropriate in terms of achieving the best education/life/social skills outcomes in autistic people?
- How can parents and family members be supported/educated to care for and better understand an autistic relative?

- How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
- How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
- How can **sensory processing** in autism be better understood?
- How should service delivery for autistic people be improved and adapted in order to meet their needs?

Are your five priority areas included in the ten listed above? Are there any important priorities that you think are missing from the survey results?

Provide your answer...

Discussion

Obviously views on the priorities will vary. Beyond the 'top ten', other areas listed included evaluating interventions for managing challenging behavior, improving social skills and exploring the most effective early interventions. Research into sensory processing was the only more theory-related item in the top ten. Researching the causes of autism was number 20 on the list.

One topic not mentioned in the Autistica report, but much in the news at the time of writing, is the finding that autism can manifest differently in females, leading to under-diagnosis. You might want to re-read the discussion of this in Week 3 Section 4.1. Also, because the Autistica survey was conducted in the UK, research priorities for autism in other parts of the world were not identified.

3.2 Doing research well

Facilitating effective autism research is not just a question of funding the right areas; it is also about how the research is done and who gets to participate. Scientific approaches such as cognitive psychology and neuroscience traditionally follow a model in which one group of people (research specialists in the field) carry out tests and gather information from another group of people (the participants).

But there has been a growing call for autistic people to play a more integrated role (Pellicano and Stears, 2011). One leading Canadian research team, headed by Professor Laurent Mottron, has been following this approach for some years, with Michelle Dawson, an autistic person, as a research team member. Dr Anna Remington, Director of the Centre for Research in Autism and Education, University College London, leads on several initiatives to ensure that autistic people inform the CRAE research activities not just as participants, but in other roles (Zeliadt, 2017).

Of course, doing research this way is not straightforward. For instance, autistic people may need to accept certain research findings which do not fit with their own personal experience. Mutual respect, trust and candid dialogue between team members is an important part of making such a process viable.

4 Autism in society

Bringing autistic people into the research process is part of a wider process of accommodating autism within society. These days, autism is of wide public interest in countries like the UK, and media portrayals have undoubtedly played a role in this. But this doesn't mean that autism is well understood: while media portrayals have enhanced general public awareness, they are also responsible for some erroneous ideas that are unhelpful when it comes to making the right accommodations for autistic people.

4.1 Media portrayals of autism

How is autism portrayed in the media? You can explore this question in the activity below.

Activity 3 Media portrayals of autism

Allow about 20 minutes

Think about the 1988 film *Rain Man* and two more recent media or fictional representations of autism. These could be films, TV series, books, etc. How accurate was *Rain Man*'s representation of autism? Do you think that media representations have become more authentic in recent works? Can you think of any portrayals of women? (Note: if you have not seen *Rain Man*, you can look up a synopsis on Wikipedia).

Provide your answer...

Discussion

It is only possible to discuss one or two of the different representations of autism here. In *Rain Man*, Dustin Hoffman plays the autistic character Raymond Babbitt with a skilful and convincing portrayal of social detachment, naivety and rigid adherence to structure and routine. Equally key to the plot, however, is Raymond's exceptional memory and powers of mental calculation, which his brother Charlie exploits to his advantage in the Las Vegas casinos. For movie-makers and writers, special or savant skills have the obvious attraction of making the character exciting, exceptional and exotically different, but as you have learned in earlier weeks, such skills are by no means representative.

In a recent portrayal of autism in fiction, Stieg Larsson, the author of *The Girl with the Dragon Tattoo*, takes the unusual and important step of portraying a female character who is strongly implied to have autism. The character Lisbeth Salander contrasts strongly with Raymond Babbitt in her independence, autonomy and capacity for deception. Yet the motif of special powers of memory and exceptional skills – IT skills, as befits the era – still surfaces in this portrayal.

A recent study (Nordahl-Hansen et al., 2017) compared portrayals of the autism spectrum in 26 films and four television series with the core symptoms in the DSM-5 criteria. Encouragingly, they found that most of the portrayals aligned well with the diagnostic criteria. However, there was still an undue emphasis on savant characteristics. The authors also expressed concern that the characters tended to be

stereotypically autistic, thus failing to portray the rich variation and individuality of autism

A Guardian article about the BBC series *The A Word* offers an interesting critique by parent Simon Hattenstone and his autistic daughter Maya (Hattenstone and Hattenstone, 2016).

An important step towards giving autism an authentic voice in the media was taken by the TV series *Holby City*. In 2016, the series introduced an autistic character, Jason Haynes, played by the young autistic actor, Jules Robertson.

4.2 ‘Coming out’

There are other ways in which the media can help to present authentic and positive images of autism. A small but growing number of personalities with successful media careers have chosen to acknowledge their autism. One such person is TV presenter and wildlife expert Chris Packham, who struggled for years with depression and a sense of being different from others. As a child he became passionately attached to animals, secretly hand-rearing a kestrel at home. The loss of this bird caused him trauma, and in adult life he suffered a deep depression on the death of his dog. It was after therapy that he was diagnosed with Asperger syndrome at the age of 42. He now says that although he worked hard to acquire neurotypical traits, such as eye contact for the sake of his TV appearances, he believes that Asperger syndrome is an important part of him which has supported and enhanced his career:

Managing my autism on national television still requires an enormous effort. Sometimes I fail, I do just go off on one. But I realise now there is no way I could do my job without Asperger's.

What I do in terms of making programmes is afforded to me because of my neurological differences. Being able to see things with perhaps a greater clarity, being able to see the world in a very visual way.

(Chris Packham: *Asperger's and Me*, 2017)

Susan Boyle, the Scottish singer who achieved fame on the TV show *Britain's Got Talent*, was diagnosed with Asperger syndrome in 2013. Like Chris Packham, she struggled with many years of adversity before receiving her diagnosis, and like him, her willingness to make her diagnosis public has offered a positive image of what people on the spectrum can achieve.

Of course, many autistic people are achieving success and fulfilment in their own fields. The ‘celebrity’ life stories mentioned above bring autism to wider public awareness, and are helpful because they are honest and authentic.

4.2 Making society autism-friendly

In the following activity you will think about challenges that autistic people may face in everyday life.

Activity 4 Challenges of autism in everyday life

Allow about 10 minutes

Think of the activities that many people engage in regularly in their daily lives. These might include travelling on public transport for work or leisure, shopping for food, or going to the cinema or a sports hall. List three kinds of challenges that an autistic child or adult might experience in doing these or similar activities. If you are on the spectrum yourself, or have autism in the family, this will not be difficult. If not, think about what you have learned in previous weeks.

Provide your answer...

Discussion

Sensory issues

Travelling on public transport or visiting a cinema or sports hall may induce unfamiliar or painfully loud noises. Shopping for oneself or with a parent may also involve noise as well as unpalatable smells, bright lights or confusing visual displays.

Social and communication issues

On a train or bus, or in a cinema or sports facility, an autistic child or adult may find the physical proximity to others anxiety-provoking and difficult to deal with. Instructions (e.g. for purchasing travel or cinema tickets) may be confusing. The person may be too shy to seek help from staff or other passengers when needed.

Structure, routine and decision-making

Travelling (e.g. to go on holiday) involves disruption to familiar routines. Shopping involves planning and making decisions about products, all of which may seem overwhelming to an autistic person.

Problems like these often serve to exclude autistic people from society: they may be too anxious to go out, travel or shop. Parents may find the prospect of a holiday with an autistic child daunting and end up staying at home. Even going shopping may be an ordeal for both parent and child.

Several UK organisations work to overcome such barriers to inclusion. The National Autistic Society (NAS) has established the Autism Friendly Award scheme. Those managing public spaces and amenities are invited to submit evidence of their 'friendliness' to autistic people in terms of five criteria, including provision of clear information accessible to autistic users of the service, well-trained staff and volunteers, and a physical environment that minimises stressors such as a confusing layout and noise.

Organisations that have received the Autism Friendly Award include several UK airports, theatres, museums and sports stadia; a handful of opticians and supermarkets; and the buildings of the Northern Ireland and Welsh Assemblies and Scottish Parliament.

A separate charity, The Autism Directory, operates its own listing of autism-friendly places, including shops, hairdressers, pubs and restaurants (The Autism Directory, 2017). An increasing number of cinema chains are providing autism-friendly screenings, for instance without advertising or trailers, lighting kept on low, reduced volume and other adjustments. Organisations such as Auticon and Specialisterne, which you read about in

Week 7, work specifically to place autistic people in appropriate jobs, and to ensure that their working environment is autism-friendly.

5 Autism in a global perspective

There are big disparities between the current situation of autistic people in developed countries and elsewhere. Despite major gaps and deficiencies in UK infrastructure and services, there is much progress compared to several decades ago, and as outlined this week many positive initiatives are ongoing. There follows a summary of some key advances in the UK, before a discussion of priorities and initiatives for some LMICs where resources are scarce.

5.1 Autism in the 21st century in the UK

These bullet points summarise some of the key advances in the autism field in the UK during the 21st century:

- Autism diagnosis now follows internationally agreed criteria and standard procedures – it did not do so in the 1960s. However, there are deficiencies and delays in the accessibility of diagnosis.
- A range of educational strategies and interventions is in use, with some measure of success. Again, though, access to schools and specialist centres with the resources to implement best practice is often extremely patchy.
- Research has provided insights into cognition, behavior, brain function and genetics in autism, as well as long-term outcomes. Yet there are huge gaps in this understanding, concerns about funding priorities and calls to inform research from an autistic perspective
- There is recognition that autism often goes undiagnosed, notably in females (Gould and Ashton-Smith, 2011), and also more widely in the adult population. Rectifying this problem, and meeting the needs of autistic adults generally, remain significant challenges.
- There have been significant changes in public awareness and perceptions of autism in which autistic people have played a key role. However, there is still ignorance and stigma, and as you have seen, the media has played a mixed role.
- Autism legislation such as the UK Autism Act 2009 and the Autism Act (Northern Ireland) 2011 are positive steps. However, the NAS and Autism NI joint report, Broken Promises, highlights failure to implement the autism strategy and action plan set out in legislation (Stewart, 2016). Similarly, The Autism Dividend, published by the National Autism Project (Iemmi et al., 2017), documents the UK-wide failure to deliver services and to source evidence-based, cost-effective interventions.

5.2 Autism in Lower and Middle Income Countries

The situation for autistic people and their families in many LMICs reflects, at considerably greater scale, the problems experienced in developed areas of the world, but with additional cultural, political and economic challenges. For instance, health priorities may focus elsewhere on problems such as infant mortality, malaria and AIDS. Public awareness and professional understanding of autism is usually limited. Even where diagnosis is available, it may be hampered by inadequate professional training.

As you saw in Week 3, there are differences across cultures in expectations about development and behavior. For instance, in parts of the world where eye contact between children and adults is culturally inappropriate, a lack of eye contact is unlikely to cause concern (Matson et al., 2011). This means that diagnostic criteria and tools based on Western ‘norms’ of child behaviour may be inappropriate for different cultures. Prithvi Perepa comments here on the importance of taking cultural context into account in identifying autism:

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Another problem is that fear of stigma may cause parents in some societies to conceal their children and avoid or delay seeking help (Kishore and Basu, 2011). The few diagnosed cases in such settings tend to be the children of more affluent parents, and to be ‘obvious’ or classic cases, while high-functioning children are likely to be overlooked. This impacts on overall public understanding of autism in these societies: as in the UK in the 1960s, autism tends to be known only as a profoundly disabling condition.

A recent worldwide autism prevalence estimate of 0.6 per cent, falling well below estimates for developed countries, most probably reflects sparse diagnosis rather than worldwide differences in the incidence of autism (Elsabbagh et al., 2012). Wallace et al. (2012) advocated internationally coordinated efforts to tackle autism worldwide. Some recent key milestones towards this global initiative include resolutions by the United Nations (2007) and World Health Organisation (2014) and the Autism Speaks ‘Global Autism Public Health’ (GAPH) initiative (2008).

To illustrate why such global initiatives are necessary, we will look briefly at autism in Ethiopia, and at a collaborative research and training initiative involving an Open University (OU) team including Ilona Roth, lead author of this course.

5.3 Autism in Ethiopia

Ethiopia is in sub-Saharan Africa, with a population of almost 100 million, of whom around 50 per cent are children, and 85 per cent based in rural areas. Despite strong growth in the last decade, Ethiopia remains one of the poorest countries in the world.

In 2012, Dr Rosa Hoekstra (now at Kings College London) led a team of specialists from the OU and Addis Ababa University (AAU) on the first research project on autism in Ethiopia. To ensure practical benefits, development of training materials was integral to the project. Previously the OU had provided health training resources for the rurally based **health extension workers (HEWs)** who, for most Ethiopians in rural areas, provide the only form of health service. These earlier training materials included a brief discussion of mental health and just a few sentences about autism.

The team conducted interviews with the few service providers in the capital Addis Ababa and looked at public documentation (Tekola et al., 2016). The emerging picture mirrored the broad picture already outlined for LMICs, highlighting low levels of awareness and high levels of stigma among the public, limited specialist training, sparse mental health services, and inadequate funding in the context of other health priorities.

The two schools for autistic children were both set up in Addis Ababa by parents of autistic boys, among the very few children to have been diagnosed. After finding that no school would take her own autistic son, in 2003 Zemi Yenus established the Nia Foundation Joy

Center for Autism, which now provides for around 80 children and offers advice, support and training to parents.



Figure 1 (left) Zemi Yenus; (right) The Joy Center for Autism.

Another parent, Rahel Abayneh, established the Nehemiah Center in 2010, also in Addis Ababa and catering for around 60 children. Both parents campaign vigorously to raise public awareness, combat stigma and mobilise practitioners and policy-makers. As of 2018, two more autism schools have opened outside the capital.



Figure 2 (left) Rahel Abayneh; (right) The Nehemiah Center.

5.4 Mental Health Pocket Guide and training videos

Continuing their research in rural areas, the team found that stigma is common, including among HEWs themselves (Tilahun et al., 2016; 2017). Stigma may be directed at the autistic individual and their family, or experienced by the family without the specific actions of others – for instance, a family may feel shame or guilt at their child's slow and atypical development. In the majority of cases where autism remains undiagnosed and the label itself is unfamiliar, stigma may arise nonetheless because a child's slow development and unusual behaviour marks them out as different. Certain traditional beliefs may have a stigmatising effect: children may be thought possessed by a spirit, and parents may believe they are being punished for a sin. One HEW gave the following account:

I have got one child in our survey; he does not talk. His parents were hiding information about him. They thought that this type of disease is cured through traditional or spiritual means. They said [his illness was] due to spirit possession – likift – because someone had given him some potion. When I saw the child he was very pale and [...] chained.

(Tilahun et al., 2016, p. 7)

The research demonstrated that the HEWs would benefit from more targeted training (Tilahun et al., 2017). In response, the team produced a guide to autism, intellectual disability and other child and adult mental health problems, including tips on supporting parents and families. In addition, the team produced five interview training videos for autism and intellectual disability.

Versions of these materials now form a free OpenLearn Create resources pack on mental health, available on this page: [Mental Health: Resources for Community Health Workers](#).

Ongoing initiatives in Ethiopia include the development of a culturally appropriate diagnostic instrument, and the trial of an intervention that can be implemented by parents with their children.

5.5 Pooling resources and practices

Looking at autism in a less well-resourced country serves to emphasise that, despite many outstanding problems and challenges, resources available in Western countries such as the UK have facilitated progress. Building on this, international research teams can share knowledge and skills, thus promoting global exchange of insights and practices. As Prithvi Perepa emphasises, this is not a one-way process: despite low resources, non-Western communities may offer progressive models from which much can be learned:

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6 End of course quiz

Now try the [End of course quiz](#) and earn yourself a digital badge.

7 End of course summary

The final week of *Understanding autism* has encouraged you to reflect on what you have learned in previous weeks, using this knowledge to consider where we are now with autism and what challenges and priorities there are for the future, whether in the UK or globally.

The final words go to Alex:

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You should now be able to:

- evaluate how your own knowledge and understanding has increased while studying this course
- appreciate both shared problems and differences in the lived experience and needs of autistic people
- discuss trends and priorities in autism research and support
- identify wider societal issues that affect the lives of those with autism and their families
- understand some of the priorities for autism in low resource settings.

Tell us what you think

Now you have completed the course, take a few moments to reflect on your experience of working through this BOC and what you have learned. Please complete the [optional survey](#) to tell us about your reflections. Your responses will allow us to gauge how useful you have found the BOC and how effectively you have engaged with the content. We will also use your feedback to better inform the design of future online experiences for our learners. Many thanks for your help.

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Week 4

Images

Figure 1: adapted from Frith, U. (1989) Autism: Explaining the Enigma, Oxford: Blackwell.

Figure 2: © Axel Scheffler

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Text

Activity 4: extract from Empathy Quotient (EQ) and Systemising Quotient (SQ) for Adults (Autism Research Centre 2018)

Audio/Video

Activity 2: © The Open University

1.4 audio: Dr Wenn Lawson ©The Open University

1.4 video: © The Open University

2.2 video (clip 1): courtesy Surrey Autism Board

<http://www.surreyab.org.uk/surrey-autism-partnership-board.html>

2.2 video (clip 2): courtesy: National Autistic Society <https://www.autism.org.uk/>

Week 5

Images

Figure 1 Based on source material provided by Gillian Roberts, Principal, Robert Ogden School, South Yorkshire, UK; Photos: PhotoEuphoria/iStockphoto; Vikram Raghuvanan-shi/iStockphoto

Audio/Video

1.1 Video: Alex: © The Open University

1.2 Video: Arabella (mother of Iris Grace) © The Open University

5.2: Video: Joe: © The Open University (2005)

6.1 Video: Queensmill © The Open University

7.4 Video Arabella (mother of Iris Grace) © The Open University

9. Video: Arabella (mother of Iris Grace) © The Open University

Week 6

Images

Figure 1: courtesy: Zoe Wood

Figure 2: courtesy: from Earlybird Support Programme: National Autistic Society

<https://www.autism.org.uk/>

Audio/Video

2.2 two clips © OU

3.1 Video: Alex © The Open University

4.4 Video: Arabella (mother of Iris Grace) © The Open University

Week 7

Audio/Video

2.2: Video Alex: © The Open University

5.2: Video: Alex: © The Open University

9. Video: Alex: © The Open University

Week 8

Images

Figure 1: courtesy Ilona Roth

Figure 2: courtesy Ilona Roth

Audio/Video

2.2: Video: Arabella (mother of Iris Grace) © The Open University

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