

Module 18: The autistic environment

This module will discuss the New Model of Autism as defined by the DSM V (Diagnostic Statistical Manual- Fifth edition 2013), and its implications regarding diagnosis.

Refere

nce will be made to the rising numbers of people that are now diagnosed with Autism and the possible reasons for this rise as highlighted in recent research. This will include the concept of Toxic Body Burden and its impact on cognitive functioning.

We will also discuss the way in which who have been diagnosed with Autism can access support (looking at UK, USA, Australia and Canada).

- 18.1 The New Model of Autism
- 18.2 Autism Spectrum Disorders Rising
- 18.3 Toxic Body Burden
- 18.4 The Government's Role

18.1 The New Model of Autism

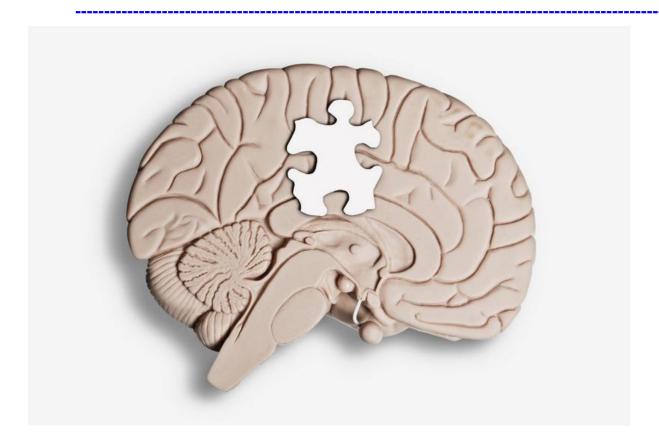
In the last module (Module 1 Analyzing the Spectrum), we looked at the criteria that is needed to provide an accurate diagnosis of Autism. To provide a common criterion that is used throughout the UK and USA for Autism, the DSM-V (Diagnostic Statistical Manual of Mental Disorders, Fifth edition) is used. The DSM also covers other medical difficulties that we will be covering in Module 9 – Medication.

Over the years there have been changes to the manual. Currently there is concern that there have been changes to the categories for Autism. This has given rise to the concern that some of the psychological tools used to determine a diagnosis for Autism are now too simplistic.

The changes in the fifth edition of the manual now mean that Asperger's, Pervasive Developmental Disorders, and Autism are now diagnosed as Autistic Spectrum Disorder I, II or III.

This now means that Rhett's Syndrome and Child Disintegrative Disorders are included in the Spectrum but are diagnosed by their severity of need within Social Communication and Ritualistic behaviors.





18.1.1 Autistic Disorder level I: 'Requiring Support'

Social Communication:

- Without support in place there is a deficit in communication ability which can cause noticeable difficulties.
- Has difficulty initiating any social interactions.
- Demonstrates clear examples of atypical or unsuccessful responses to the approaches of others.
- May appear to have little or no interest in social interactions.

Restricted interests and Repetitive Behaviours:

- Rituals and repetitive behaviours cause significant interference and difficulty in their daily lives and general functioning.
- This disruption affects more that one area of their lives.
- Resistance of any attempt by others to be distracted from their fixated interest.

Children and people assigned to this level would definitely be at the high end of the spectrum, namely what was earlier referred to as Asperger's Syndrome.



18.1.2 Autistic Disorder Level 2: 'Requiring Substantial Support'

Social Communication:

- Marked deficits in verbal and non-verbal communication skills.
- Social impairment even with support in place.
- Limited initiation in social interaction
- Reduced or abnormal response to the social approaches of others.

Restricted interests and Repetitive Behaviours:

- Restricted Interests and Repetitive Behaviours that are very frequent and are obvious to the casual observer.
- The Restricted Interests and Repetitive behaviours interfere with many activities and general daily functioning.
- The child or adult become very distressed and frustrated if there is any attempt to distract them from their interests and repetitive behaviours.
- It is extremely difficult to divert their interest if at all.





18.1.3 Autistic Disorder Level 3: 'Requiring Very Substantial Support'



Social Communication:

- Severe deficits in verbal and non-verbal communication skills. Language may be absent.
- There deficits cause severe impairment for any functioning.
- Very limited initiation of social interaction if at all.
- Minimal response of the social approaches of others.

Restricted interests and Repetitive Behaviours:

- Total preoccupation with fixated rituals and repetitive behaviours that occur all of the time.
- Very distressed if the rituals are interrupted.
- They immediately return to their interest and/or rituals if interrupted.



18.1.4 Does Asperger's Syndrome still exist? (1 of 2)

With the new model of Autism is means that that Asperger's Syndrome which was added to the DSM 1994, has existed for a short period of time, was removed in May 2013. Which begs the question does Asperger's still exist? In official terms 'no', because the diagnosis would be Autistic Spectrum Disorder Level I.

The reason for diagnosing what was Asperger's as Autistic Spectrum Disorder Level I, is that in general terms the need is 'of a low level of support'. On the face of it that is correct but the type of low level support that is needed has to be of a different genre than for someone who is ASD Level III.

However, to just give a label of ASD Level I, is not sufficient. Autism at whatever level affects each child or adult differently. On a personal level, I have encountered clients with similar traits but how the traits impact on their lives will depend on their personality; levels of sensitivity; resilience and the effectiveness of their support.

To counteract the impact of ASD level labelling, there should be specific descriptors to highlight individual signs and symptoms. The use of Care Passports will be discussed in later modules of this course, as they are now widely used in the UK within hospitals and care facilities.

Asperger's may not exist as a definitive within the DSM V, but clinicians will still carry on using the international coding system especially when they are dealing with medical insurance companies (USA), as Asperger's is still included in that system. Groups and organisations that support their members that have Asperger's will continue to use the descriptor.

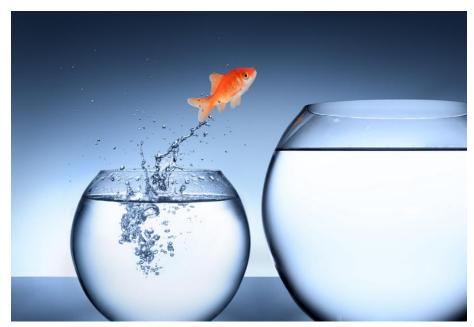
18.1.4 Does Asperger's Syndrome still exist? (2 of 2)

Nevertheless, no matter how controversial these changes are, they were based on sound research, analysis and expert opinion. The aim of the changes to the DSM, were made in the hope that diagnosing Autistic disorders would be more reliable, more specific and hold more validity.

There is apprehension as to how the changes will impact people who will no longer meet the stricter criteria for diagnosis, especially people at the higher end of the spectrum. Will they still be eligible for the support that they have had within education? This is concerning especially as it is likely that they also have additional learning difficulties.

Obviously these changes will have an impact not just in the people who are diagnosed with Autism, but also their families.





Since the publication of the DSM-V, scientists have found that there is distinct brain connectivity difference between children with Autism in comparison with children who have other forms of Autism, and that children with Asperger do not have a speech delay but children with other forms of Autism do.

18.2 Autism Spectrum Disorders Rising

18.2.1 Some of the current statistics (1 of 2)

- About 1 percent of the world population has autism spectrum disorder. (CDC, 2014)
- 1 percent of the adult population of the United Kingdom has autism spectrum disorder. (Brugha T.S. et al., 2011)
- Prevalence of autism in U.S. children increased by 119.4 percent from 2000 (1 in 150) to 2010 (1 in 68). (CDC, 2014) Autism is the fastest-growing developmental disability. (CDC, 2008)
- Boys are 5 times more likely to be affected than girls.
- In the USA, it is estimated that 1 in 68 children are diagnosed with ASD, which is a 30% increase on the 1 in 88 back in 2012. The numbers are very similar in the UK. What is more concerning is that the numbers have sharply risen since the 1980's.
- Prevalence has increased by 6-15 percent each year from 2002 to 2010. (Based on biennial numbers from the CDC)
- 35 percent of young adults (ages 19-23) with autism have not had a job or received postgraduate education after leaving high school. (Shattuck et al., 2012)
- Autism services cost U.S. citizens \$236-262 billion annually. (Buescher et al., 2014) In 10 years, the annual cost will be \$200-400 billion. (Autism Society estimate)





(http://www.autism-society.org/what-is/facts-and-statistics)

18.2.1 Some of the current statistics (2 of 2)

Looking at the numbers you don't have to be a statistician to work out that the number of people who are being diagnosed with Autism is rising steeply. The cost of supporting people with autism through education and other services is sharply rising. We need to look at why these numbers are rising so sharply.

There are some major questions that need to be acknowledged:

- Is the incidence of Autism truly on the rise?
- Do the statistics just reflect the growing awareness of the condition?
- Does the definition of Autism need to change?
- If cases of Autism are on the rise, what is the cause?

These questions are being asked by parents, psychologists, psychiatrists and researchers.

One important aspect to focus on is that since the 1990's the definition of Autism has expanded to include other disorders such as Asperger's Syndrome and Pervasive Developmental Disorder (PDD)



Also included in this list is Oppositional Defiant Disorder (ODD), which shares some elements of Autism.

A child who is diagnosed as Autistic by recent criteria (DSM IV, DSM V) may have been diagnosed as retarded in the 1980's. It was not until 1992 that schools classified Autism under Special Education Needs. Classification also changed in psychological reports on cognitive ability (Retarded as a classification became Special Educational Needs).

18.2.2 Causes of Autism Spectrum Disorders Rising

More recently it is thought that there is more than one explanation for the rise in the cases of Autism.

- Research that has focused on the possible causes has concluded that only 1 in 10 people who have been diagnosed with Autism have a definitive cause.
- The other 9 out of 10 people diagnosed with Autism are a puzzle as there is no apparent definitive cause.

The lack of a definitive cause is usually confounded by the presence of other problems:

- Depression
- Anxiety
- Gastrointestinal problems
- Seizures
- Genetics (including twin studies. It has been found that if one twin has Autism, then the other twin has a 75% chance of being affected as well.)
- Metabolism disorders
- Neurological disorders

What researcher have agreed on is that there is more than one cause and in the majority of cases there may be a combination of factors that cause Autism.

In cases where one child in a family has Autism there is an 8% chance of siblings also being Autistic.

18.3 Toxic Body Burden

If we look back to the last section, where it was stated that the 9 out of 10 people who were diagnosed with Autism were a mystery as there was no apparent cause, yet several theories have tried to offer a solution. The most notable one was the blame that was attached to the vaccination for childhood diseases.



The doctor, who led the research into vaccinations being a possible cause of Autism, was branded a scare monger. Many parents opted out from the vaccination programme through fear of their child becoming Autistic The doctor was discredited and parents were encouraged to continue with vaccinating their children against childhood diseases.

It was found that it was not the vaccination itself was the possible cause of Autism, but in all probability the mercury that was used in the suspension and delivery of the vaccine could be a the problem.

Metals such as lead and mercury are already known to be pollutants which in high enough exposure carries risk to the human body and influences behaviour. This is particularly the case when a young child is exposed to these metals.



18.3.1 Toxic Body Burden - Environmental Triggers

A variety of environmental triggers could be the cause of the elevated incidences of Autism in recent years, not just exposure to lead and mercury. Other toxic substances include pesticides, environmental pollutants such as the ones found in fluorescent lighting equipment and antibodies from the mother reacting with fetal brain tissue.

Pesticides



- Research compared 465 children diagnosed with Autism with 7,000 children without Autism.
 The study focused on whether the mothers of the children lived near agricultural areas that used pesticides.
- It was found that the higher amount of pesticides that were used, the closer proximity of the mother to that area, the higher the incident of Autism

PCB's (Polychlorinated Biphenyls)

- This substance is found in electrical equipment. It was used extensively in the past. PCB's
 although are no longer produced are still lingering in the environment especially where
 florescent lighting and old electrical equipment is used.
- PCB's are known neurotoxins.

Maternal Immune system

- Research continues into the interaction of genes and the environment. The concern is that the maternal immune system plays a large role in late development of Autism in a child.
- In a study that examined blood samples from 163 mothers (61 had children with Autism, 62 had children without Autism and 40 had non-autistic developmental delays). The samples were used on brain tissue from a fetal tissue bank. It was found that antibodies from the mothers with Autistic children were more likely to react to the fetal brain tissue.

18.3.2 Toxic Body Burden - Studies

Research work by Altaf Alabdali and colleagues in Riyadh, discovered that when they analyzed blood samples from children that were diagnosed with Autism against a control group, there were some interesting differences.

- Levels of lead and mercury were 30-40% higher in the samples from the children that were diagnosed with Autism than the control group.
- The results also indicated that the children with Autism had reduced Vitamin E, and detoxification mechanisms that would enable the body to rid itself toxic substances.
- It was concluded that the accumulation of toxic metals impaired the metabolic system. This would account for a child having normal development, and then demonstrating signs of impaired development.
- It was also suggested that the findings that the Toxic effect of these metals culminated over a period of time to perpetuate Autistic symptoms.

This study is not the only study in the area of Toxic Body Burden and the authors of this work continue with their investigations. Although there is still some controversy and speculation about the source of exposure to the metals, it is imperative that research continues especially because of the link between the low levels of detoxification and Autism.



The importance is that there is growing support for a combined model of both genetic and environmental factors that can offer a cause of the elevated rates of Autism in populations.

18.4 The Government's Role

As the number of people diagnosed with Autism continues to rise dramatically there is a call on the government to put more finance into research and support.

If we look at the statistics for the US (the rate if diagnosis and support is mirrored in statistics in UK, Canada and Australia), it becomes imperative that Autism is expensive to support and families cannot always compensated for reduced funding.

- The cost of support for one person with Autism is about \$2.4 million or \$1.4 million for a person without intellectual disability. (Buescher et al., 2014)
- The average cost of educating one student per year is \$12.000. the average cost of educating a student with Autism is \$20,600 (NCES, 2014)
- Currently, less than 17% of disabled people in the US are in employment. (Bureau of Labor Statistics, 2014)

Not all research into Autism is government funded; much of the research is paid for by the larger Advocacy groups. One of the larger Autism advocacy groups has called on the government to increase its research funding as it is an investment. The thought is that by researching the cause of Autism it will reduce the financial impact of support needs in the long term.





Additional concern is that in the light of statistics regarding the prevalence of Autism, that funding for research has not been increased it has been reduced. The questions that need to be acknowledged through research is 'what is the cause of Autism' but 'how can we effectively treat it'.

18.4.1 The Government's Role - Getting help

The main theme of the rest of this section is that not everyone associated with and trained to work with children have qualifications or awareness to understand the signs and symptoms of Autism.

At one stage in the UK there was some confusion between the symptoms for high functioning Autism and Schizophrenia. This led to several people being treated for schizophrenia when they were actually Autistic. Different governments impose different criteria for qualifications.

18.4.2 The Government's Role - UK

In the UK, there are usually three ways that support can be accessed



- Through an assessment by an Educational Psychologist. This is usually access by the parent discussing concerns with the class teacher or the SENCO (Special Educational Needs Co-coordinator).
- If the child is younger, then the pathway is through the family doctor or health visitor who will
 refer on to the Speech and Language Therapist for an initial assessment. The SLT will then
 refer on to the pediatric Clinical Psychologist to be evaluated.
- There are several private services that are available but the difficulty is usually getting statutory services to provide support if a child has been assessed privately.

18.4.3 The Government's Role – USA and Canada

USA

- If the child is over the age of 3, contact should be made to the local Board of Education, to get an evaluation by the local school board.
- Not all school boards cover the cost of the assessment. Those that do cover the cost of assessment because of mandates support for early identification of students with difficulties.
- Assessments can be done privately by medical professionals that are trained to diagnose Autism.
- Not all schools will accept an assessment that is completed by a Psychologist, they will require an assessment an diagnosis from a Developmental Pediatrician.
- Not all insurance companies will fund Autistic assessments unless the child has other medical difficulties such as seizures or gastrointestinal difficulties (or any of the other medical difficulties that will be covered in Module 9)

Canada

• The family doctor will refer to a specialist for assessment.

18.4.4 The Government's Role - Australia

Australia

The first move should be to talk over concerns with the family doctor, who will advise on an assessment at one of the assessment centers.



The important difference in Australia is that all pediatricians are trained to diagnose Autism. So there is not a need to wait for additional assessments by specialists.

18.4.5 The Government's Role - Support

Different governments provide different levels of support and different financial benefits depending on the severity of the difficulty that the person with Autism is experiencing.

In the UK, some of the following additional support may be accessed.

- Access to DLS (Disability Living Support) which allows a child or adult to access services and support that helps them to take part in activities that they normally would not have access to.
- Respite care. This allows a level of independence as well as a break for the immediate carer of the Autistic person.
- Support in school to help negotiate change and differing social situations.
- Support for and Learning difficulties that may also be experienced in addition to Autism.

Support depends on the level of difficulty experienced. It should also be noted that support has diminished because of government cut backs over the past 6 years.

EXAM LINK