

AUTISM

Introduction

The understanding of Autism Spectrum Disorder (ASD) has evolved. According to the NHS (2022), ASD is a neurodevelopmental condition that creates differences in social communication, behaviour, and sensory processing. Children may display this by making little to no eye contact, having difficulty maintaining and making conversation and making inappropriate facial expressions and tones of voice (National Institute of Mental Health, No date). Repetitive behaviours are also a core symptom of ASD. These include hand flapping, twirling, and jumping (Cadwell-Harris, 2021). Despite advancements in recognising and diagnosing ASD, challenges persist. This poster explores the process of diagnosis, the barriers faced by children and families with ASD, and a strategy used to support ASD.

Diagnosing

Early diagnosis and treatment of ASD are crucial for better outcomes (Gabbay-Dizdar *et al*, 2021). The earlier the diagnosis in childhood, the sooner the child has the opportunity for early intervention (Okoye *et al*, 2023).

Issues with diagnosing

- 172,022 individuals awaited ASD assessments with 5.9% receiving a first appointment within the recommended time frame (NHS, 2023a).
- Between July and September 2023, children with suspected ASD waited an average of 10 months for an assessment (RC Psycho, 2023).
- Multidisciplinary assessment that evaluates developmental history, behavioural observations and standardised assessments. No medical test (Centers for Disease Control and Prevention, 2022b).

Assessment is given based on the National Institute for Health and Care Excellence (NICE) guidelines which include autism-specific tools should be used (NICE, 2017).

Autism Diagnostic Observation Schedule (ADOS)

- Standardised framework and coding system ensure validity and reliability (Frans, 2019) and (Zahle, 2021).
- Study shows it is a superior diagnostic tool compared to others (Zander *et al*, 2014).
- Specialised training is available to ensure the tool is being used effectively (Zauder, 2023).

Barriers

One Notable barrier to autism is the emotional impact the diagnosis and autism have on parents and carers. Parents may struggle to come to terms with and accept a diagnosis (NHS, 2020).

- Parents feel an emotional and social burden following a diagnosis (Papadopoulos, 2021).
- Major transitions cause stress and impact family dynamics (Rfat *et al*, 2023).
- Parents feel emotions of guilt, shame and emotional breakdown as well as thoughts of fear and concern for the future (Barak-Levy and Paryente, 2023).
- A constant emotional and physical toll for parents due to the responsibility of providing optimal care, advocating for their children's needs and driving force behind their child's growth and development (India Autism Center, 2023).
- Raising a child with ASD costs twice the cost of raising a typically developing child. Consequently, parents have higher stress, smaller support networks and more anxiety (Montest and Cianca, 2014).
- Communication challenges may impact the relationship between the parent and the child (Hands Center for Autism, 2022).

Another Barrier to ASD is sleep disturbances. According to NHS (2021) sleep difficulties are common in children with ASD for multiple reasons including sensory sensitivities, difficulty with regulating sleep-wake cycles (National Autistic Society, 2020b), and the lack of melatonin production (Carmassi *et al*, 2019). Sleep impacts all aspects of development including cognitive functioning, emotional regulation, and social interactions (Schiliber and Han, 2021). As well as attention, memory, and problem-solving skills (Jiang, 2019). Specific to children with ASD, lack of sleep can increase irritability, hyperactivity and aggression (Deliens *et al*, 2015).

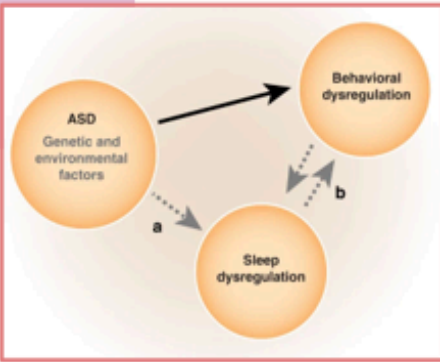
Supporting strategies

Applied Behavior Analysis (ABA) is one supporting strategy used for ASD. ABA systematically analyses behavior to identify patterns and factors influencing behavior, designs interventions based on this analysis and then evaluates the effectiveness of the interventions (Fisher *et al*, 2021). ABA can support language, social and communication development, reduce challenging behaviors and improve cognitive functioning (Autism Speaks, No date). ABA is individualised and tailored to the unique needs, preferences and strengths of each child (Child Autism UK, no date).

Conclusion

In conclusion, ASD involves various experiences, challenges and needs, explaining the need for timely diagnosis and effective intervention strategies. The barriers faced by children and their families should be recognised to ensure effective support is given. While the diagnosis process is challenging, early identification and access to support are essential. Applied Behavior Analysis therapy is a strategy that is individualised and is shown to improve outcomes in children with ASD.

Source: Mielig *et al* (2020).



Good afternoon everyone, I am Lydia and this webinar will discuss and explore the diagnosing process of Autism, also known as ASD, the barriers faced by children and families with ASD, and a strategy used to support children with ASD.

The definition of autism has evolved and could potentially be revised in the future when there is a deeper understanding of it (National Autistic Society, 2019). According to the NHS (2022), ASD is a neurodevelopmental condition that creates differences in social communication, behaviour, and sensory processing. Centres for Disease Control and Prevention (2022a) supports this and states that the abilities of people with ASD vary. One child with ASD may be completely non-verbal while the other may have advanced conversation skills. Other signs and symptoms include lack of eye contact, making inappropriate facial expressions (National Institute of Mental Health, ND) and repetitive behaviours such as hand flapping (Cadwell-Harris, 2021).

About 1 in 100 children have autism (World Health Organization, 2023) and as shown on the census, an average of 12% of children were diagnosed with Autism in Wales in 2022 (Welsh Government, 2023). According to Gabbay-Dizdar *et al* (2021), early diagnosis and treatment of ASD are crucial for better outcomes. This was shown in their research that emphasised the clear correlation between the age of diagnosis and longitudinal change. Children diagnosed before 2.5 years of age were nearly three times more likely to experience a decrease in the severity of social symptoms compared to those diagnosed later in childhood. This is supported by Okoye *et al* (2023) who emphasised the benefits of early diagnosis. The earlier the diagnosis in childhood, the sooner the child has the opportunity for early intervention. This early intervention enhances developmental outcomes and improves adaptive skills. However, Fernell *et al* (2013) state that there is insufficient evidence to suggest that early intervention programs for autism significantly alter the long-term outcomes for most individuals diagnosed early with autism.

NHS (2023a) data highlights a significant issue: in December 2023, 172,022 individuals awaited autism assessments, with merely 5.9% receiving a first appointment within the recommended timeframe. Meanwhile, between July and September 2023, children with suspected autism waited an average of ten months for an assessment after their initial referral (RC Psych, 2023). Despite the Welsh Government's introduction of the Additional Learning Needs and Educational Tribunal Act (2018) to provide a person-centred

approach to identifying needs and offering effective support, lengthy diagnostic waiting times prevent children from accessing timely interventions. Consequently, this delay impacts academic achievement, and development, and increases the risk of mental health problems (National Autistic Society, 2023).

The process of diagnosing autism can be challenging as there is no medical test. This evaluation considers various factors, including developmental history, behavioural observations, and standardised assessments (Centers for Disease Control and Prevention, 2022b).

Rhiannon - what does the practitioner do if they suspect autism?

Well, there are guidelines that should be followed. Generally, in maintained settings, practitioners should discuss the child's needs with the ALENCO and begin to form an IDP. These documents should include a summary of how the child has suspected ALN and the date it was suspected. Parents are then notified and meetings are made with them to discuss the process. A referral should then be made within 20 days (Welsh Government, 2021). This code was influenced by the United Nations Convention on the rights of the child, article 23, that states governments must do all they can to support disabled children and their families (UNICEF, 2019).

Following a referral, the assessment is given, following advice adapted from the National Institute for Health and Care Excellence (NICE) guidelines. The NICE guidelines state that every child should have a physical examination and be considered for another diagnosis. The guidelines also state that autism-specific tools should be used to gather information (NICE, 2017).

The most common tools used in the UK are the Autism Diagnostic Observation Schedule (ADOS), the Diagnostic Interview for social and communication disorders (DISCO) and the Autism Diagnostic Interview (ADI-R) (Ambitious about Autism, 2022).

Brook- what is the most used diagnostic tool?

ADOS is the most widely used diagnostic tool for autism. It is a semi-structured, standardised assessment (National Autistic Society, 2020a). It can be used with people of all ages, abilities and language skills (NHS, No date). It consists of a series of activities and tasks that are relevant across different developmental levels and age ranges (SO *et al*, 2022). Trained observers use a predefined coding system to record the presence or absence of specific behaviours shown by the child during the assessment. These behaviours are scored based on their relevance to the diagnostic criteria for autism (Akshmooff *et al*, 2006).

The ADOS offers several benefits. Firstly, it provides a standardised framework for assessing social communication and interaction behaviours associated with ASD. This consistency ensures the validity and suitability of the information gathered (Frans, 2019). The validity and reliability are also enhanced due to the predefined coding system. The ADOS uses a systematic collection of observational data, reducing the potential for bias in the assessment process (Zahle, 2021).

Romesh and Reddy (2022) state that standardised testing is an efficient way to show reliable comparisons across individuals and settings. However, SO *et al* (2022) state that ADOS may not be as suitable for all genders, as there is ongoing evidence to show different presentations in symptoms across genders. Consequently, the same standardised test may not be suitable for everyone. This is supported by a study published by Rogers *et al* (2016) who found that clinicians raised concerns regarding validity when detecting ASD symptoms in females as females present differently to males.

As well as gender differences, a study by Hus and Segal (2021) found that diagnosing autism was difficult in social-cultural families. For example, a lack of eye contact is a common symptom of non-verbal communication in ASD in Western cultures. However, In the Chinese culture, it is considered impolite if children make direct eye contact with adults. This difficulty could lead to a misdiagnosis.

Additionally, a study by Zander *et al* (2014) found that the ADOS was superior to other diagnostic tools however the best diagnosis validity was found when a combination of tools were used together. This is supported by Zander *et al* (2015) who state that additional assessment methods should be used alongside the ADOS to develop a comprehensive picture of the child's needs and this is further supported by SO *et al* (2022) who state that the ADOS cannot be the only tool used to diagnose as ASD is often accompanied by

other neurodevelopmental and behaviour disorders such as ADHD. This then complicates the diagnostic process and could lead to the potential for misdiagnosis. For instance, Roberts (2022) states that social anxiety disorder can present in the same way as ASD as the symptoms include difficulty being social, eating with company and avoiding eye contact (NHS, 2023b).

As well as training to diagnose, ADOS training is also available for clinicians to become certified in administering and scoring the ADOS. This training ensures that clinicians are using the assessment tool effectively (Zauder, 2023). This enhances the quality and accuracy of diagnostic evaluations. However, despite trained clinicians, there are unavoidable barriers during the diagnostic process such as the presentation of masking. ASD individuals can hide their symptoms and mask their behaviours. If this occurs there is a possibility of delayed or missed diagnosis (Estrin *et al*, 2021). Highlighting the need for multiple diagnosing tools.

BARRIERS

Moving on from the identification and diagnosis of autism, I will now discuss the barriers to autism.

One notable barrier to autism is the emotional impact the diagnosis and autism have on parents and carers. Parents may struggle to come to terms with and accept a diagnosis (NHS, 2020).

Makino *et al* (2021) found that the most common reaction to a diagnosis of ASD was relief and other positive aspects due to finally getting an explanation for their child's behaviour for which they are not to blame. However, Papadopoulos (2021) states that mothers feel an emotional, family and social burden following an ASD diagnosis. According to Rfat *et al* (2023), parents may feel family burdens during the diagnosing process due to its major transitions, including their educational transition. This stress can impact family dynamics.

This is supported by research by Barak-Levy and Paryente (2023) who found most parents felt emotions of guilt, shame and emotional breakdown as well as thoughts of fear and concern for the child's development and future during a diagnosis. Naicker *et al* (2023) states that parents who accept their child's diagnosis have greater parental well-being.

Moreover, one of the most significant lasting impacts of having a child with ASD is the ongoing emotional and physical toll it takes on parents. Parents have a responsibility to provide optimal care, advocate for their children's needs and drive force behind their child's growth and development (India autism center, 2023). According to Montest and Cianca (2014), raising a child with ASD costs at least twice the cost of raising a typically developing child. As a result, these parents have higher stress, smaller support networks and more anxiety. This is supported by Ou *et al* (2015) and Zablotsky *et al* (2015) who state that ASD is associated with severe employment and financial burdens. The studies found that having a child with ASD decreased the odds of living in a higher-income household as some families have to reduce working hours or completely stop working.

Additionally, children with ASD can often have communication challenges. These difficulties may impact the relationship between the parent and the child (Hands Center for Autism, 2022).

Theorists such as John Bowlby emphasise the importance of the attachment bond between children and their primary caregivers. According to Bowlby, secure attachment provides a foundation for healthy emotional development and influences the child's interactions throughout life (Holmes, 2014).

Another barrier to ASD is sleep disturbances. Sleep disturbances and difficulties are common challenges faced by many children with ASD for various reasons. One contributing factor is sensory sensitivities, as many individuals with ASD are hypersensitive to sensory stimuli, making it challenging for them to settle down and relax enough to fall asleep (NHS, 2021).

Additionally, individuals with ASD may have difficulty regulating their sleep-wake cycles, leading to irregular sleep patterns and insomnia (National Autistic Society, 2020b). Studies have also suggested that children with ASD produce less melatonin at night (Carmassi *et al*, 2019). According to NHS (2023c), melatonin is a hormone that helps control how and when a person sleeps.

The impact of inadequate sleep on the development and lifestyle of children and families with ASD should not be underestimated. Sleep plays a vital role in numerous aspects of development, including cognitive functioning, emotional regulation, and social interactions (Schiliber and Han, 2021). Lack of sleep can impair cognitive processes such as attention, memory, and problem-solving

skills, impacting academic performance and learning opportunities (Jiang, 2019). This is supported by Contie (2022) who found that children who do not get enough sleep are at risk for long-term harm to the brain.

Additionally, Specifically with children with ASD, sleep disturbances can increase behavioural challenges associated with ASD such as irritability, hyperactivity and aggression. This will impact the quality of life and negatively affect the mental health of parents and caregivers (Deliens *et al*, 2015). This is further supported by Kansagra (2020) who states that lack of sleep is associated with poor mood and emotional regulation as well as an increased risk of anxiety.

Many theorists emphasise the importance of sleep for optimal development. For instance, Maslow's Hierarchy of Needs provides a framework for understanding the significance of sleep as a fundamental physiological need essential for human growth and well-being (Main, 2022).

Strategy

I will now explore a support strategy for ASD. Multiple strategies and interventions can support children with ASD. Applied behaviour analysis also known as ABA is a type of therapy. It involves systematically analysing behaviour to identify patterns and factors influencing behaviour, designing interventions based on this analysis and then evaluating the effectiveness of these interventions (Fisher *et al*, 2021).

One of the key strengths of ABA therapy is that it is individualised. ABA programs are tailored to the unique needs, preferences and strengths of each child, ensuring that interventions are highly personalised and effective (Child Autism UK, No date).

A study by Yu *et al* (2020) found that ABA-based interventions were beneficial to the lifelong development of children with ASD. This is supported by Gitimoghaddam *et al* (2022), Pitts *et al* (2019), and Autism Speaks (No date) who found that after ABA there was improved cognitive, language, social/communication, challenging behaviour and autism symptoms.

Moreover, ABA therapy is not without its criticism and limitations. In the 1970s when ABA was discovered, there were previously practised techniques that were seen as punishment and violations of rights including forced prolonged eye contact and withholding basic needs (Advanced Behavior Analysis, 2022). However, ABA therapy today has evolved and is seen as a respected therapy. Today there is a high demand for ABA and there is a long wait list for it to become available. Schools that provide it are also at maximum capacity (Kirkham, 2017).

However, despite the development and evolution of ABA, there is an ongoing debate within the autism community regarding its alignment with principles of neurodiversity. The National Autistic Society (No date) believe that some ABA interventions used today are still too intensive and are not sufficiently person-centred.

It may also be seen as a limitation due to its cost. Research shows that ABA therapy may not be cost-effective and is unlikely to represent value for money (Hodgson *et al*, 2022).

Conclusion

In conclusion, the journey through ASD involves various experiences, challenges and needs, highlighting the importance of timely diagnosis, and effective intervention strategies. ASD presents uniquely in each individual, emphasising the need for multiple approaches to support their development and well-being. Understanding and supporting autism requires recognising the barriers faced by children and their families such as the long waiting times for diagnosis, the burdens faced by families of children with ASD and the impact lack of sleep has on children with ASD and their families. While the diagnosis process can be challenging, early identification and access to appropriate support can significantly impact outcomes. Applied Behaviour Analysis therapy, with its individualized approach and evidence-based interventions, offers a strategy that addresses the unique needs of children with ASD.

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