

Interpretation of Tourette's Syndrome in the Early Years

Introduction

The objectives of this informative poster are to define the identification and diagnosis of Tourette's Syndrome, and to explore in depth the barriers and support strategies which can be adopted for children in the early years. According to Senedd Cymru (2022), Tourette's syndrome affects 1 in 100 children, which signifies that it is not a rare neurological disorder, and it can be exhausting and painful for the child. Additionally, Hamilton and Harrison (2024) express that early diagnosis and support is important for children, because of the effect on their cognitive processes and executive functions.

Identification and diagnosis of Tourette's Syndrome

According to the National Health Service (2021), the definition of Tourette's Syndrome is a condition that affects a person by causing involuntary tics, which can be both physical and verbal. However, both Wen *et al.* (2018) and Carias and Weurick (2019), argue that Tourette's Syndrome often comorbidly exist with other neurodevelopmental disorders, such as Obsessive Compulsive Disorder, Autism and Attention Deficit Hyperactivity Disorder. Furthermore, Groth *et al.* (2019) and Paulus *et al.* (2021) state that this is a persistent childhood neurodevelopmental disorder that is diverse, and therefore can be difficult to diagnose.

Alade and Maricle (2020) also express that diagnosis is not categorised by severity, as it is viewed as a vast spectrum with various impairments.

As a result, this can cause Tourette's to be difficult to diagnose, because the symptoms can often be mistaken for other neurological conditions, or a developmental phase (NINDS, 2023).

Support strategies for children

Whilst Tourette's Syndrome is currently incurable (Rothenberger and Roessner, 2019 and National Health Service, 2021), there are a number of support strategies that can be practiced to support children with Tourette's. Ludlow, Cutler and Keville (2022) and Conelea *et al.* (2024), encourage a support strategy for children in mainstream schools, which is educating teachers and peers about the condition, and managing this accordingly within the classroom, which they believe is important for not only inclusivity in correspondence with global laws, but that a collaborative approach also has the greatest influence on positive outcomes for the child. Nevertheless, Mulholland and O'Connor (2016) and Solvason and Winwood (2022) argue that this approach faces barriers, which include, time restraints, limited training and opportunities for professional development, lack of resources and specialised support.

Pine *et al.* (2024) report that Tourette's can affect children's learning due to the tics often being exhausting, thus affecting concentration, and hindered motor and vision which are all dominant skills for writing and reading.

Dabrowski *et al.* (2018) and Chen *et al.* (2020) suggest that Habit Reversal Training can help to create an awareness of detecting a tic, and the child is then taught to apply a specific movement or verbal sound to stop the exhibition of the tic which is considered to be the most effective method of intervention.

However, Fernandova *et al.* (2017) report that this therapy is inaccessible due to limited specialised therapists in the National Health Service, and Montalbano *et al.* (2022) argue that this method can be unsuitable for some children because of limited motivation to change the behaviour, if it is not causing any distress to them.

Inclusion

Boyle (2020, p.1-4) believes that inclusive practice is difficult to define, and this has led to a challenge in whether mainstream education is suitable for all children, and if the system is adaptable and flexible enough to meet the needs of the individual child, rather than the child being made to fit the system. Pit-ten Cate *et al.* (2018) concurs with Boyle and proclaims that facilitating inclusive practice can be a barrier for teachers, as they have apprehension of their ability to manage a more diverse classroom, and often feel incompetent, leading to a preference of children with additional needs being accepted into specialised schools to support their development. Furthermore, the Additional Learning Needs Code for Wales 2021 (Welsh Government, 2021, p.40-41) state that the Welsh Government underpin an inclusive education, and that the system relies on the expertise of staff to analyse appropriate methods of providing access to the curriculum for every child. It also declares that meeting the individual needs of children is a whole school approach, applying staff's knowledge of each individual child's abilities and skills.

Conclusion

By examining the evidence above, it is clear to regard that early detection and diagnosis is imperative for supporting children with additional needs in the early years. Although there are many support strategies that can support children with additional learning needs, adopting the right approach for the child can be challenging due to several barriers including budget, time constraints and a lack of support. However, supporting children's individual needs is of upmost importance, in ensuring accessibility and inclusion for all children.

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Webinar Script

Good evening, my name is Cheryl Davies, and welcome to my contribution to this evening's webinar.

Tonight, I will be defining the identification and diagnosis of Tourette's Syndrome, and exploring in depth the support strategies which can be adopted for children in the early years, and the barriers that children and practitioners can encounter.

According to Senedd Cymru (2022), Tourette's Syndrome affects 1 in 100 children, which signifies that this is not a rare neurological disorder, and the tics can be exhausting and painful.

The National Health Service (2021) report that the definition of Tourette's Syndrome is a condition that affects a person by causing involuntary tics, which can be physical or verbal. Similarly, Kious, Jimenez-Shahed, and Shprecher (2016) define Tourette's Syndrome as a neurodevelopmental condition which can be complex and is distinguished by tics and is often linked with psychiatric co-occurring conditions.

Conversely, symptoms can vary between genders.

Garris and Quigg (2021) and Wellen *et al.* (2023), state that although Tourette's is more predominant in males, and they are more likely to have Attention Deficit Hyperactivity Disorder, as they grow older the symptoms decrease. However, they reported that in females, they are more likely to suffer with anxiety and mood disorders, and their tics do not improve with age.

On the contrary, Baizabal-Carvallo and Jankovic (2023) and Larsh *et al.* (2023) argue that the contrast in symptoms between males and females has not been fully examined or explored to date.

According to Hamilton and Harrison (2024), early diagnosis and support is imperative for the child, because of the effect on their cognitive process and executive functions, and according to Tourette's Action (2020, p.3-5), once a diagnosis has been received, the child can access support networks and strategies, and gain a better understanding of themselves.

However, both Groth *et al.* (2019) and Paulus *et al.* (2021) state that this is a persistent childhood neurodevelopmental disorder that is diverse, and therefore can be difficult to diagnose. Furthermore, NINDS (2023) report that Tourette's can be difficult to diagnose because the symptoms can often be mistaken for a developmental phase, or other neurological conditions.

Nilles *et al.* (2024) and Pringsheim *et al.* (2023) provide an example of this, by documenting that Coronavirus has impacted neurological effects in the brain due to biological, social and psychological stressors, and as a result, this has caused an increase of functional tic behaviours in children globally, which mirror Tourette's Syndrome symptoms.

Wen *et al.* (2018) and Carias and Wevrick (2019) both argue that Tourette's Syndrome often comorbidly exist with other neurodevelopmental disorders, such as Obsessive Compulsive Disorder, Autism and Attention Deficit Disorder. Erbilgin Gün and Kilincaslan (2019) coincide with this view, by stating that comorbid disorders are prevalent in close to 90% of patients with Tourette's Syndrome, and there is emerging evidence to establish links to Autistic Spectrum Disorder as well as the above.

Szejko and Müller-Vahl (2021) also assert that although the predominance of patients with a primary tic disorder is a more straightforward process, differentiating the diagnosis can be demanding because of the cross section of symptoms with comorbid OCD and ADHD. Demartini *et al.* (2015) agree, and state that using methods of diagnosis can still cause misdiagnosis, due to psychosomatic symptoms being common with these comorbid neurological disorders.

Nevertheless, National Health Service (2021) and Torres (2022) contend that various tests and scans by specialists are used to diagnose Tourette's Syndrome, which can be used to rule out other medical and neurodevelopmental disorders. Yet, Alade and Maricle (2020) express that as diagnosis is not categorised by severity as it is viewed as a vast spectrum with various impairments, this can result in diagnosis difficulties.

Whilst Tourette's Syndrome is currently incurable (Rothenburger and Roessner, 2019 and National Health Service, 2021), there are a number of support strategies that can be practiced for children with Tourette's Syndrome.

Providing the child with support strategies in practice is required by law. This is enshrined in the Additional Learning Needs Code for Wales 2021 (*Welsh Government*, 2021, p.38), the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994, p.8-9), and the United Nations Convention for Disabilities (no date, p.4-5). In these statements and laws, it is underpinned that reasonable adjustments, adaptations, awareness that every child has a right to an education and person-centred practice must be adopted to ensure inclusivity for the child.

Sandall (2019, p.189), concurs with these statements, by declaring that inclusion in the early years with children with additional learning needs is supported by research and law, and is an expanding reality in our divergent communities. Regardless of these facts, Jawed and Peck (2022) argue that our healthcare system is not equipped to provide enough support for children with additional needs, and that units for neurodivergent children could provide optimal support and care management, and used as a bridge until a child is accepted into a specialised school.

Similarly, Boyle (2020, p.1-4) asserts that inclusive practice is difficult to define, and this has led to a challenge in whether mainstream education is suitable for all children, and if the system is adaptable and flexible enough to meet the needs of the individual child, rather than the child being made to fit the system. Pit-ten Cate *et al.* (2018) concurs with Boyle, and proclaims that facilitating inclusive practice can be a barrier for teachers, as they have apprehension of their ability to manage a more diverse classroom, and often feel incompetent, leading to a preference of children with additional needs being accepted into specialised schools to support their development.

However, Ravenscroft, Wazny and Davis (2017) are convinced that children with additional learning needs need to be included into mainstream schools, with each individual child provided with additional support, and that children are at the centre of all decisions that affect them. This is also underpinned in the United Nations Convention on the Rights of the Child (Unicef, no date) under Article 23, where it states:

“A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.”



This is also supported by the Education Act 1996, where in Sections 316-317, it governs that mainstream schools must provide a responsible person that correlates provision for children with additional learning needs, and also be educated in a mainstream provision on the condition that resources are suitable for the child and does not impact the provision of systematic education for other children (legislation.gov, no date).

Furthermore, the Additional Learning Needs Code for Wales 2021 (*Welsh Government*, 2021, p.40-41) state that the Welsh Government underpin an inclusive education, and that the system relies on the expertise of staff to analyse appropriate methods of providing access to the curriculum for every child. It also declares that meeting the individual needs of children is a whole school approach, applying staff's knowledge of each individual child's abilities and skills.

Yet, Banks, McCov and Frawley (2018) declare that specific interventions are required to promote positive experiences for children with additional learning needs in mainstream provision, because they believe that children with additional needs find it difficult to develop relationships with their peers, which they are convinced that proves that these children will not benefit socially and emotionally from inclusive education. Koller, Pouesard and Rummens (2018) agree with this, and believe that children with additional learning needs can be a victim of social exclusion, due to facing an increased probability of being bullied or isolated by their peers, which has an impact on the child's well-being, participation and becoming a valued member of the school community.

Nevertheless, under the Convention on the Rights of Persons with Disabilities (United Nations, no date) under Article 24, it is established that individualised support measures must be provided in environments, to facilitate effective education and with the goal of full inclusion, including materials and educational techniques for support.

To help overcome these barriers, Ludlow, Cutler and Keville (2022), and Conelea *et al.* (2024) encourage a support strategy for children with additional needs in mainstream schools, which is educating teachers and peers about the condition and additional learning needs of the child, and how to manage this in the classroom, which they believe is important for not only inclusivity in correspondence with global laws, but that a collaborative approach also has the greatest influence on positive outcomes for the child.

Mingbunjerdasuk and Zinner (2020) acknowledge this view, by affirming that a collaborative approach that collects the views of the child, along with the parents, school staff and clinicians, can help to develop a deep understanding of the child's strengths and difficulties, and therefore provide the child's peers and educators with psychoeducation. Although they state that this may not be efficient enough to reduce stigmas, it can help to develop resilience in the child, and help educators develop a plan towards de-escalation, and provide suitable educational resources and accommodations.

Despite these positive impacts for the child, Mulholland and O'Connor (2016), and Solvason and Winwood (2022) argue that this approach faces barriers which include time restraints, limited training, resources, lack of opportunities for professional development and specialised support for care givers. Furthermore, Nussey, Pistrang and Murphy (2014) recognise that there is limited research into this form of intervention, and to the effectiveness that this has on supporting the child with Tourette's.

In addition to these barriers, Fletcher *et al.* (2021) reports that educating children with Tourette's in school is impaired by educator's lack of understanding and knowledge about the disorder, which highlights the need for this service to be provided. However, they also call attention to the barriers for this service, which include cost, timeliness, lack of information shared by parents, and difficulty with diagnosis for the child.

In contrast to these barriers, according to the Additional Learning Needs Code for Wales 2021 (*Welsh Government*, 2021, p.44-66), an educator supporting a child with additional needs should understand any support that a child requires, and the local authority has a duty to consult relevant agencies in order to support the care and development of the child with additional needs and offer opinions on any emerging needs and the suitability of expertise in the workforce for the child. This guidance highlights the importance of understanding the child's additional learning needs, in order to provide the best holistic support and care possible (M2 Presswire, 2018).

Eördegh *et al.* (2020) report that frequent motor and verbal tics can cause moderate adjustments to some cognitive executive functions for a child with Tourette's Syndrome, which includes verbal fluidity, short term memory and a delayed response time, also known as the 'Stroop effect'.

Pine *et al.* (2024) agree with this statement, and also report that Tourette's syndrome can affect children's learning, due to the tics often being exhausting. Tan *et al.* (2023) believe that the reason for this is because of psychosocial stress and anxiety, which can increase the severity and frequency of the tics, which Lee, Wang and Lee (2022) are convinced leads to lower self-esteem, poor social adjustment and discrimination.



However, Dabrowski *et al.* (2018) and Chen *et al.* (2020), suggest a way to support children with tics through an intervention called Habit Reversal Training. They are convinced that this method can help to create an awareness of detecting a tic, and the child is then taught to apply a specific movement or verbal sound to stop the exhibition of a tic, which they consider to be the best method of intervention.

Although there is a strong argument for this intervention method, Fernandova *et al.* (2017) and Viefhaus *et al.* (2021) report that this therapy is often inaccessible due to limited specialised therapists in the National Health Service, and Montalbano *et al.* (2022) argue that this method can be unsuitable for some children, because of possible limited motivation to change the behaviour, for the reason that the tics are not causing any distress to them.

Furthermore, Asheville Citizen (2018) reports another barrier to this method of intervention, which is that in many instances, the care giver will often need to investigate and assess to discover the exercises that are successful for the individual child's tics.

Nonetheless, Li *et al.* (2022) contend that this is an increasingly popular method of intervention, due to its effectiveness and safety, and promotion of mindfulness, wellbeing and reduction in anxiety and depression. Dabrowski *et al.* (2018) believe that the reason for these positive influences is due to attuning self-awareness, relaxation training and functional analysis, which results in a multi element form of intervention.

Additionally, under the Additional Learning Needs Code for Wales 2021 (*Welsh Government*, 2021, p.39-41), it states that early identification of an additional learning need, and prompt application of interventions are crucial for children to succeed and participate in an education system that meets their individual needs. This legislation also highlights the importance of delivering an appropriate intervention strategy to prevent the risk of ineffective methods of intervention. This legislation also proposes that caregivers also capitalise on a variety of strategies, to support a continuity of assistance to reflect the child's individual needs and progress.

Moreover, ensuring that a child with additional learning needs is incorporated in inclusive practice, the diversity of individuals is respected and appreciated, and early interventions includes corresponding with the families of the child with additional needs, as well as every network that relates to the child, to ensure that the child is considered as unique, and the correct support is available for the child to thrive (Early Years Matters, 2023).

This right is also enshrined in the United Nations Convention on the Rights of the Child (Unicef, no date), under Article 29, where it states:

“Education must develop every child’s personality, talents and abilities to the full. It must encourage the child’s respect for human rights, as well as respect for their parents, their own and other cultures, and the environment.”

To conclude, considering all the evidence above, interventions and support for children with additional needs is not an exclusive strategy, and interventions require knowledge of the unique child, and a deep understanding of the child’s strengths and difficulties. Furthermore, early detection and diagnosis is imperative for supporting children with additional needs in the early years, to ensure individualised support that enables the child to lead an inclusive, accessible, non-discriminatory and fulfilling life.

That brings me to the end of my discussion, thank you all for listening. Does anyone have any questions?

Ashley: Good evening, Cheryl, you mentioned that Tourette’s is not a rare condition, so what causes Tourette’s syndrome in children?

A: Thank you, that’s a great question. According to National Health Service (2021), the cause of Tourette’s is currently unknown, although it is believed to be a neurological condition. Tourette’s Action (2024) agree with this statement, by coinciding that it is a neuro-developmental condition, as the tics appear to evolve as the brain develops in early childhood. Furthermore, the Centres for Disease Control and Prevention (2023) state that environmental factors can also be a factor in causing Tourette’s, for example low birth weight, smoking during pregnancy and complications during pregnancy. However, as Tourette’s Action (2024) state, this link is still being investigated, and there is not enough evidence to confirm the cause of Tourettes.