

# Supporting Children with Tourette Syndrome in Early Years Care and Education

Module Code ECEY6006  
Student Number 1003350  
Word Count 1087

## Introduction

According to Freeman-Ferguson (2022) Tourette's Syndrome affects approximately 1% of children and young people. The British Medical Journal (2021) defines Tourette's Syndrome as a complex neurodevelopmental disorder which is characterised by motor and vocal tics which usually begin in childhood. Carroll and Robertson (2003) describe tics as a sudden, rapid, involuntary movement or sound that has no purpose or rhythm. Robertson and Baron-Cohen (1998), Carroll and Robertson (2003), Chowdhury (2004) and Stern (2021) states that Tourette's Syndrome varies widely between patients, tics can be simple or complex, for some it may be mild, but for others motor and vocal tics can be dramatic, often distressing and sometimes even disabling.

## Identification and Diagnosis

According to Chowdhury and Murphy (2016), Tourette Syndrome typically emerges at around age six to seven years old (although often transient tics may be noticeable from around age three), with Woods (2018) stating that the most common tic to begin with is eye blinking, and then as the child develops tics tend to emerge from head down and from simple to complex. Chowdhury and Murphy (2016) states that tics will fluctuate in difficulty and regularity (often referred to as waxing and waning) and this can often hinder a diagnosis, as an official diagnosis of Tourette Syndrome can only be made if a child has demonstrated one or more motor and one or more vocal tic for over a period of a year. Tourette's Action (2022a) states that an official diagnosis can provide a support network and a clear outline of the child's condition, how it affects them and any support that may be beneficial. This is important for the child, their family, peers and any professionals and adults working with them. A diagnosis can also provide a line of protection from discrimination and enable professionals to access training and further information. Stern (2021) states that the first line of treatment for a child with Tourette Syndrome is diagnosis, as this allows for recognition of the condition and for the child, family and professionals to be able to learn to understand it. Furthermore, Novotny, Valis and Klimova (2018) puts forward that early diagnosis and intervention is key to providing the support required to limit the impact upon wellbeing and the social burden of the condition. However, according to Malli and Forrester-Jones (2021) knowledgeable health care practitioners who understand and can offer a diagnosis is limited in the UK.

## Legislation in Wales

According to Welsh Government (2021), the Additional Needs and Education Tribunal (Wales) Act 2018, along with the Additional Needs Code for Wales 2021, provides a statutory system in Wales for all professionals in education. The system aims to meet the needs of children with additional learning needs, focusing on the importance of early identification and early intervention, to safeguard that children are supported fully, overcoming barriers present and enabling children to reach their full potential. Welsh Government (2021) also state that the system places a duty on professionals to have due regard to the United Nations Convention on the Rights of the Child 1989, the Rights of Children and Young Persons (Wales) Measure 2011 and the United Nations Convention on the Rights of Persons with Disabilities 2006.

## Barriers

Novotny, Valis and Klimova (2018) considers that Tourette Syndrome is complicated disorder which can notably challenge the daily life of the child and their family. According to Stern (2021), Tourette Syndrome can have a negative impact upon a child's confidence and self esteem. Furthermore, Kallol and Warner (2021) suggests that the condition can cause difficulties in social, emotional and physical development in children and challenges in function and academic abilities. Research carried out by Wadman *et al.* (2016) found that difficulty concentrating in school and the negative responses from peers and school staff were the most common challenges that children faced in education. According to Tourettes Action (2022b), children can often suppress their tics when at school and this takes a lot of concentration and focus, this can result in a lack of focus upon their set tasks. Wadman *et al.* (2016) study reflected that 82% of those asked, reported that concentration in school was difficult and 71% reported that tasks which were time limited were extremely challenging.

A study by Newman (2009) found that public perception of Tourette Syndrome is that it is a behavioural condition rather than a neurological impairment, and this can impact upon how children with Tourette Syndrome can be perceived by others in the educational setting. According to Thomas (2020), there has always been a negative social stigma attached to disability, often portrayed by the media, which is usually due to lack of understanding of disability. Malli and Forrester-Jones (2021) suggest that Tourette Syndrome is often viewed through the medical model of disability as something that needs to be treated, and while it is often the case that medication or behavioural treatment can be offered, addressing the social stigma that arises with the condition should become the focus.

## Strategies

As part of the commitment to person centred practice, Welsh Government (2019) that One Page Profiles will provide a useful working record for staff members to learn about the child, to understand their condition and how it may affect them and what staff can do to support the child effectively.

According to Pembrokeshire County Council (2021) a One Page Profile is the basis of person centred care and it aims to balance what a child needs and what is important to them. There are 3 main elements:

- Appreciation,
- What is important to the child.
- How best to support the child.

Sanderson (2014) considers that a One Page Profile is a simple way of communicating the most essential information required to ensure that a patient or child is treated fairly and each adult has a basic understanding of the child's needs and how to offer support as necessary.

## Conclusion

To conclude, Tourette Syndrome is a complex disorder which can affect children and families in many ways. Society's lack of understanding can raise difficulties for a child diagnosed with this condition, particularly affecting their self esteem and confidence. However, while there may be some academic barriers to address, Tourette Syndrome does not affect the ability of a child and therefore with support from those around them who are educated on the condition and how it affects the child, there is no reason why children cannot achieve their full potential in school and adult life. Working together, training, education and sharing information is key.

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