

DADS/Empower Project & Tourette's Support NI

Presentation to Mid Ulster District Council
Development Committee

Thursday 21st October 2021



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Empower Project is a community project funded by The National Lottery Community Fund NI. The Empower Project is led by a community organisation called DADS (Dyslexia, Autism, Dyspraxia Support) which has been operating for over 20 years and was originally set up as a self-help group for parents who have children with learning difficulties.

During this time, we have touched the lives of thousands of families all over Northern Ireland by supporting them, being the listening ear, teaching families new skills and strategies to help them with their children and acting as an advocate for families working with statutory agencies



In 2015 DADS in partnership with the NRC (Northern Regional College), Magherafelt was successful in developing a 5-year project called the Empower Project funded by The National Lottery Community Fund NI where parents, the wider family circle, and professionals were offered information sessions, training sessions, parent and professional conferences, activities for the children and siblings, coffee mornings/support meetings for parents.



Recently we have been able to offer parents and professionals the opportunity to achieve a CACHE Level 2 Certificate in Understanding Autism and OCN Level 2 in ADHD. Since 2015 11,000 participants have engaged in Empower Activities.



Since January 2021 we have moved into a 2 year extension programme piloting a Social Enterprise concept by introducing a small cost for some or all activities to allow the DADS group to try and sustain its current activities after the funding ends in December 2022



The Empower Project has recently been supporting a local family whose child was being monitored for ASD. His parents became concerned about his involuntary body and vocal tics. These behaviours were causing problems for the child both at school, at home and in all social situations. We began suspect Tourette Syndrome.



The Empower tried to get statistical evidence about this condition in Northern Ireland. They discovered that no statistics were actually available so it was felt that there was little/no support for these children with Tourette's

A call was made on social media to find out if there were many families locally with children who had Tourette's and to our amazement we had 10 families contact the Empower Project



What is Tourette Syndrome?

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Tourette Syndrome is a neurodevelopmental (brain condition) which can be lifelong or children can grow out of it.

Tourette's is not rare; As many as 1 in 100 individuals show signs of Tourette Syndrome- most of them remain undiagnosed, misdiagnosed, and/or misunderstood.

Tourette's is genetic and affects males more than females

There is no cure and no medical test that can tell you if you have it. These children are referred to CAMHS for intervention and are often prescribed drugs to help the condition.

Tourette Syndrome begins in childhood between the ages of 2-18. The average age of onset is between the ages of 6-8. Most people associate Tourette's with verbal or physical Tics.



So, what are Tics?

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Tics are an involuntary, repetitive motor movement or vocalization

Sometimes children shake their heads every few seconds or blink their eyes or twist their wrists which makes learning in school very difficult. They may also use curse words or other socially inappropriate phrases.

Other students may tease, make fun off and imitate the tics because they don't understand.

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Criteria for Diagnosis

Diagnosing Tourette Syndrome is a long and difficult process

There are few experts in this field



To get help a child must:

Have at least 2 motor tics

Have at least 1 vocal tic

Tics do NOT have to be concurrent

Childhood onset before the age of 18

There has to be at least one year since the onset of first tic in most circumstances.

This creates major problems for both the children and their parents



MOTOR TICS

Simple Motor Tics: Eye blinking, grimacing, nose twitching, leg movements, shoulder shrugs, arm and head jerks, etc.

Complex Motor Tics; Hopping, clapping

Complex Motor Tics; Hopping, clapping, throwing, touching (self, others, objects), funny expressions, sticking tongue out, kissing, pinching, tearing paper or books, echopraxia (repeating actions), copropraxia (obscene gestures)

Vocal Tics:

Simple Vocal Tics: Whistling, coughing, sniffing, screeching, animal noises, grunting, throat clearing.

Complex Vocal Tics: Linguistically meaningful utterances such as – “I’ve got it”, “Oh boy”. “Now you’ve seen it”.

Speech Atypicalities: Unusual rhythms, tones, accents, intensity of speech, stuttering



Other types of Vocal Tics:

Echolalia: Involuntary repetition of someone else's words

Palilalia: Involuntary repetition of one's own words

Coprolalia: Involuntary utterance of curse words or other socially inappropriate phrases or sentences.

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Other Tics: (Not everyone with tics has Tourette Syndrome)

Transient Tic Disorder of Childhood: One or two tics that last from a few weeks to a few months, don't change and eventually disappear.

Chronic Motor and Vocal Tic Disorder: One or two tics appear in childhood never change and never go away.



The nature of Tics:

- Naturally wax and wane
- Change in appearance and frequency
- Change in severity and intensity
- Can sometimes be suppressed for short periods of time
- Can be suggestible
- Can appear to be purposeful
- Tics seem to worsen during pre-puberty and puberty

Environmental factors that may impact Tourette Symptoms:

Stress

Fatigue

Holidays

Hunger

Anxiety

Excitement

Illness

Life & School Transitions

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Suppression of Symptoms can result in:

Worsening symptoms

Inability to concentrate on task at hand

Shutting down

Fatigue and/or worsening of symptoms at end of day

Classroom meltdowns

Often explosion of symptoms at home



How has the Empower
Project helped these
children with Tourette
Syndrome?

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Here for You

Promoted Tourette's Awareness month (15th April – 15th May) with a video from a local child –Deaglan McCallion

The National Lottery Communications Team made contact with BBC to take a short video with Deaglan, his parents and Manager of Empower emphasising the need for more research and support

A What's App group has been developed for parents to support each other and share experiences.

A get together was organised for parents and children in Seamus Heaney Centre Bellaghy.



Set up a community group called Tourette's Support NI
Formed a Facebook page with Deaglan McCallion
designing the logo

With the help and support of Cllr Ian Milne met Deputy
First Minister Michelle O'Neill

Attending an awareness and promotion evening in
ASDA Cookstown on Tuesday 26th October to try and
make staff and customers aware of Tourette Syndrome
and promote acceptance.



Tourette's Support NI aim to offer the following:

Regular support meetings for parents

A range of activities and outings for children with Tourette's and their friends

Awareness and promotion campaigns in local communities and with statutory agencies

A Facebook page for sharing information

Social media platforms for engagement and interaction between parents and children









As you can see Deaglan and all the children who have Tourette Syndrome need help and support. Their childhood has been damaged and they feel isolated and often humiliated. Deaglan's message to society is short and to the point.

“Be Kind”



What are we asking for?

We want the Council to understand the nature of neurodiversity. One in 4 of the population has a learning difficulty. Apart from Tourettes we have ASD, ADHD, OCD leading to depression, anxiety, aggressive or explosive behaviour, lack of social or emotional skills. Very often accompanied by an inability to communicate their pain.

We want the Council to let us train both their members and their staff to understand these conditions.



We want the Council to push learning difficulties and support families as they would for children who have obvious physical disabilities

We want the Council to understand that there is no difference between being blind, being deaf and being mentally challenged.

We want the Council to work with us, continue to support us and help to fund into the future the work we have begun.



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