Making Work Work for Tourette syndrome: Developing a Strengths-Based Employment Passport

The Constance Owens Liverpool Award for Service Development

Authors and Affiliations

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INTRODUCTION

Adults with Tourette syndrome (TS) frequently experience barriers to obtaining and sustaining employment despite bringing valuable strengths to the workplace. Current research indicates lower employment rates, experiences of stigma, co-occurring conditions and misunderstanding of tics are key barriers. To inform the development of a practical workplace support resource, Tourettes Action's (TA) Therapies and Advocacy service conducted a survey exploring employment experiences, strengths, challenges and effective adjustment needs among adults with TS.

METHODOLOGY

A mixed methods online survey was distributed through TA networks to adults with TS or related tic conditions. The survey explored employment status, workplace strengths, tic-related challenges, sensory and executive functioning factors, physical impacts including pain and fatigue, compulsions, and workplace adjustments. Quantitative descriptive statistics and qualitative responses were analysed to identify themes relevant to workplace support and the development of a Tourette's Employment Passport (TEP).

DEMOGRAPHICS

A total of 152 responses were received from across the UK. Most participants were employed full-time (48.7%) or part-time (25.7%). 133 respondents had a primary diagnosis of Tourette syndrome, 34 had functional tic like behaviours (FTLBs) and 23 had a chronic motor or vocal tic disorder. Participants worked across a variety of settings and services including home and office working, health and education roles, retail, hospitality, digital, active-outdoor and laboratory settings.

RESULTS

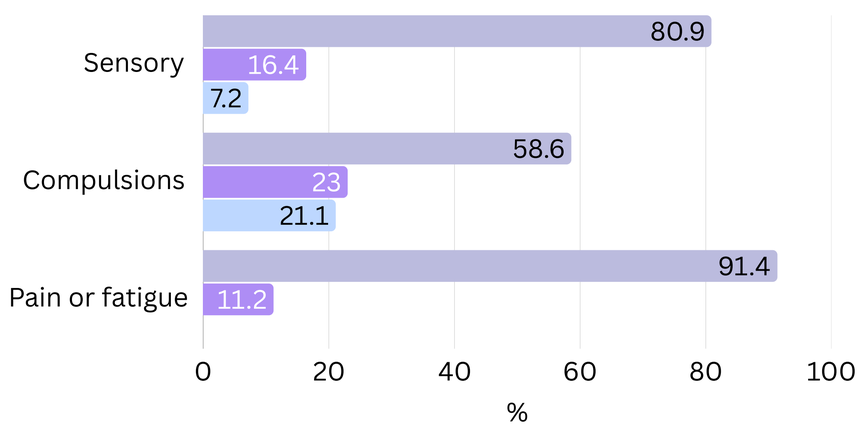
Mean tic impact at work rating

6.3 / 10

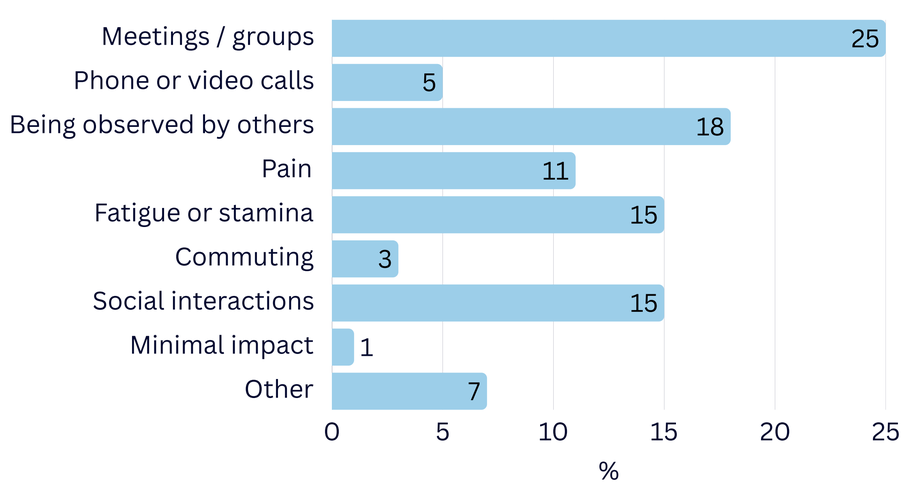
Mean self-reported psychological safety when ticcing at work rating

5.29/10

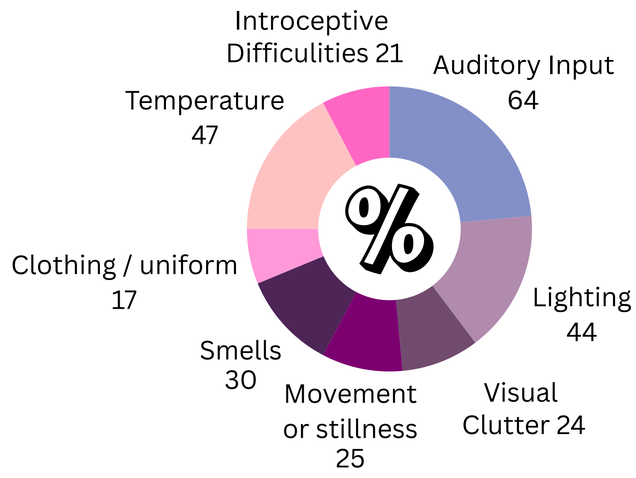
Factors which impact work



Workplace experiences which impact tics

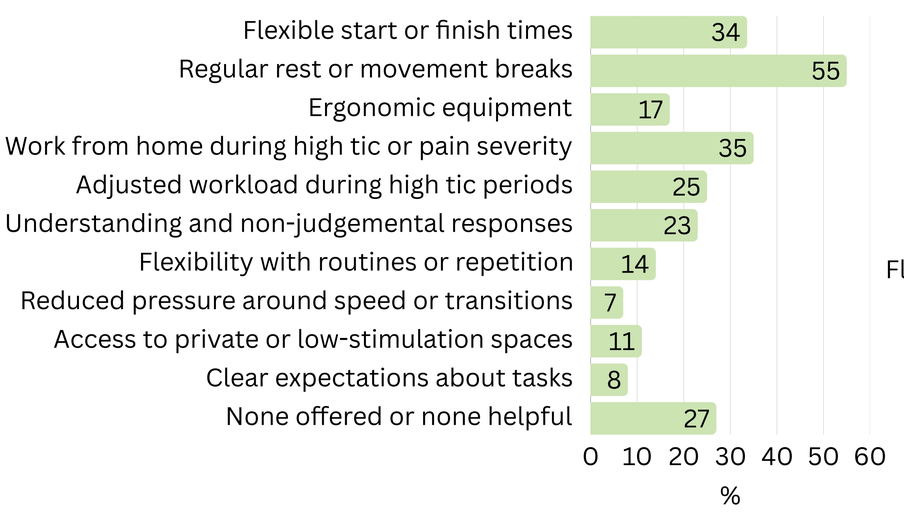


Sensory experiences which impact work

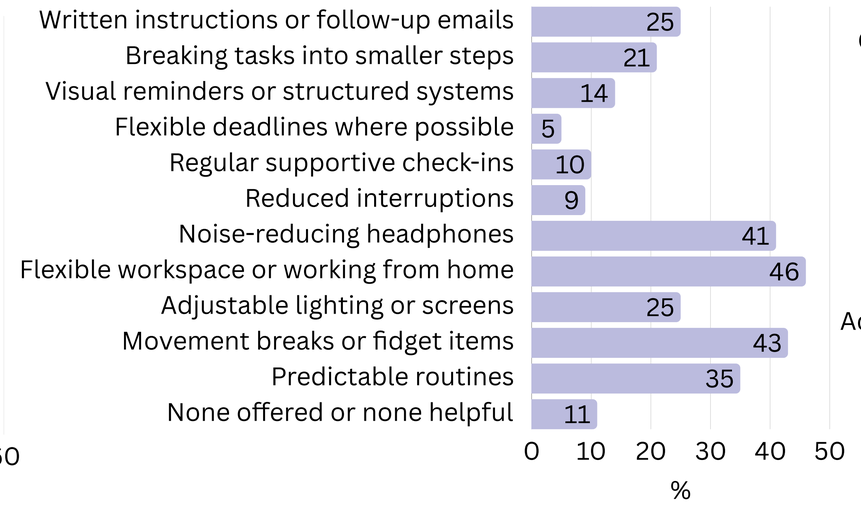


Executive Function needs which impact work

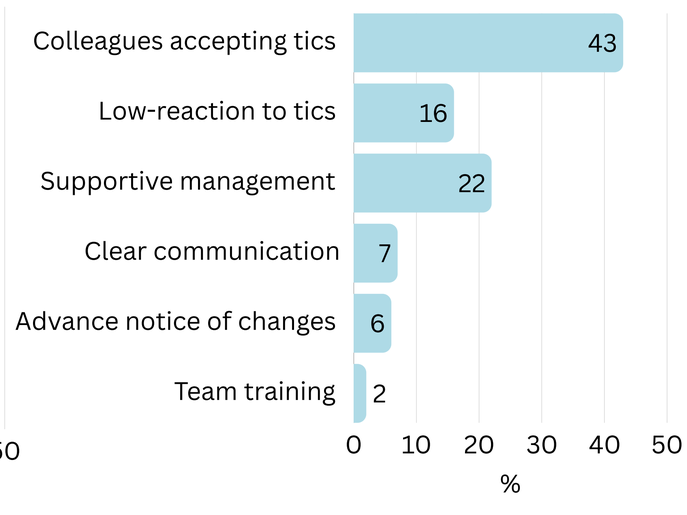
Helpful workplace task and process adjustments



Helpful Executive Function and Sensory Adjustments



Protective workplace factors



Workplace strengths and skills (n=152)

- Empathy (65.1%)
- Attention to detail / patterns (61.8%)
- Honesty and direct communication (57.2%)
- Creativity / original thinking (56.6%)
- High productivity on areas of interest (53.9%)
- Problem-solving (53.9%)
- Ability to work independently (51.3%)
- Persistence and determination (49.3%)
- High energy and enthusiasm (31.6%)
- Other: Humour, compassion, reflexes, adaptability

CONCLUSION

Findings highlight the complex interaction of neurological, sensory, cognitive and environmental factors influencing employment participation in adults with TS. Alongside strengths, participants reported barriers including tic visibility, fatigue, compulsions, sensory environments and executive function demands.

The co-produced TEP will incorporate an employee workbook for individuals to explore and reflect on workplace strengths and needs and a two page summary profile which can be shared with employers which will include key personalised adjustments relevant to the individual's needs and setting.

Tic Attire: Exploring Tic-Related Pain, Injury and the Co-Design of Protective Clothing

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INTRODUCTION

Tic-related pain and injury (TRPI) in Tourette syndrome (TS) and related tic disorders including functional tic like behaviours (FTLBs) can significantly limit participation in daily activities. Pain often results from repetitive, forceful movements and environmental interaction, including neck and limb hyperflexion, object-directed tics (e.g. hitting surfaces), and self-directed behaviours such as self-hitting. These may lead to acute injury (e.g. bruising, soft tissue damage) and chronic musculoskeletal pain. The Tic Attire project explores the feasibility of co-designed protective clothing to reduce injury without restricting movement or suppressing tics.

METHODOLOGY

An online mixed methods survey examined TRPI experiences, healthcare use, coping strategies, and design priorities. It was distributed nationally via Tourettes Action and locally through a Surrey support group. A total of 147 respondents participated. Findings were analysed to inform development of an initial protective hoodie prototype. Qualitative feedback was gathered at a face to face support group where participants could try the first working prototype.

DEMOGRAPHICS

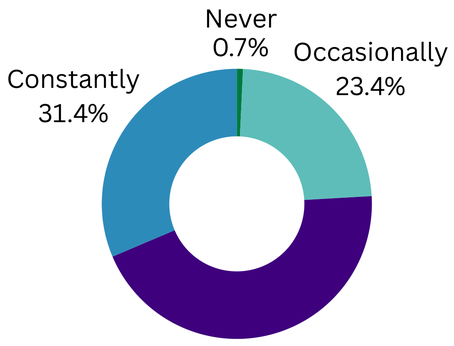
Respondents		
Adult with tics	A young person with tics (under 18)	Parent or carer of a young person with tics
98	21	28

Gender			
Man	Woman	Non-binary	Prefer not to say
41	90	14	2

Diagnosis						
Tourette syndrome	Chronic Motor tics	Chronic Vocal tics	FTLB	Stereotyped movements	Other	No formal diagnosis
109	13	4	20	2	6	16

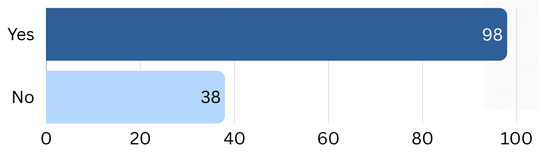
RESULTS

Frequency of TRPI

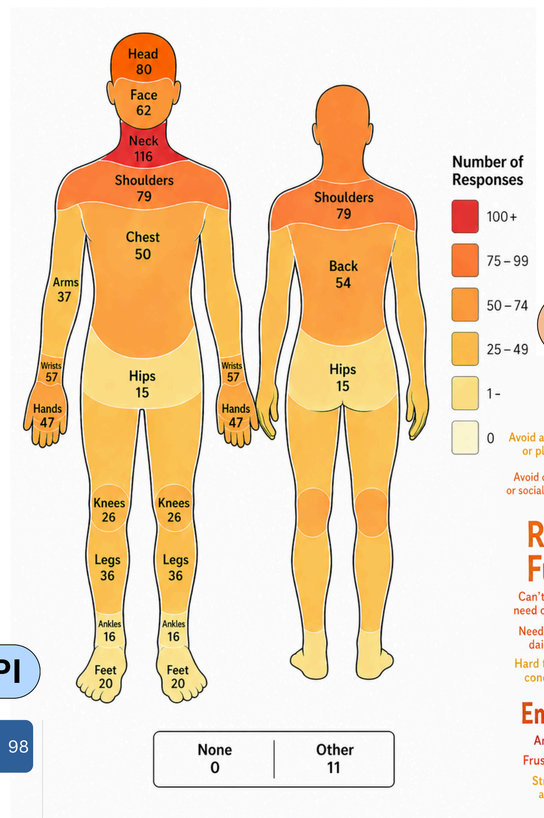


Mean TRPI severity 0-10

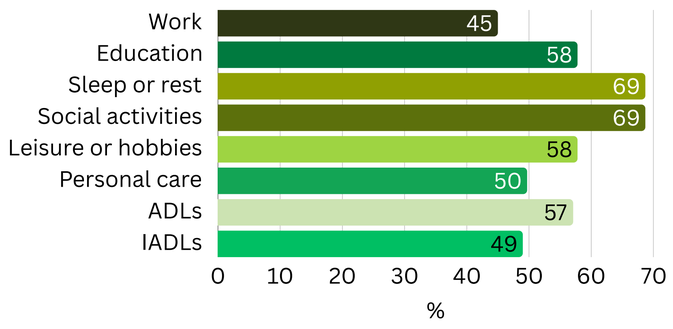
Activity Avoidence due to TRPI



Body parts most frequently impacted by TRPI

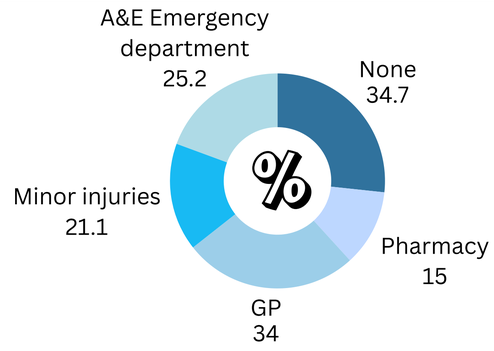


Occupational Impact of TRPI

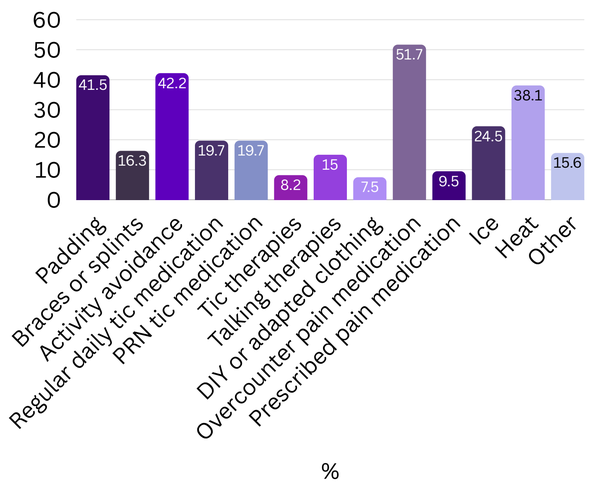


Qualitative themes of occupational impact

Treatment accessed due to TRPI



TRPI self management strategies



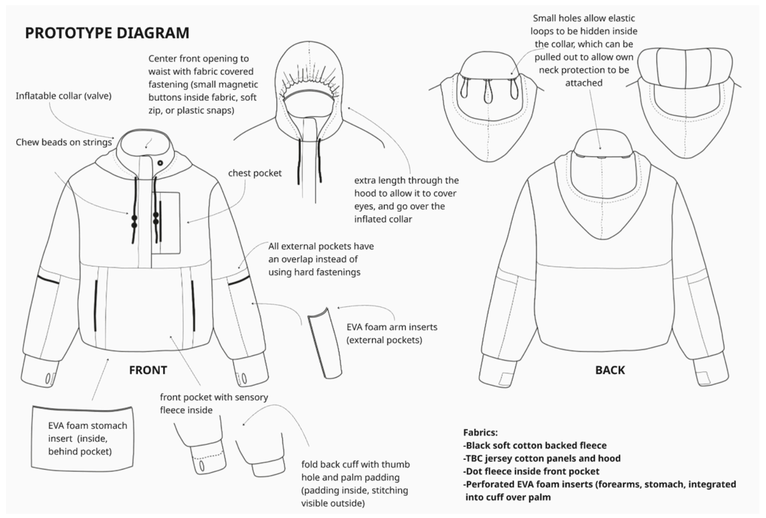
OUTCOMES

Survey findings informed the co-production of a padded hoodie prototype targeting high-risk areas, including the hands and neck, designed to be comfortable, discreet, and sensory-informed.

A key priority identified by participants was that the garment should not appear medical or clinical; therefore, the hoodie is intentionally styled to resemble everyday clothing.

Features include a discreet, hidden inflatable pillow to reduce range of hyperextension during head and neck tics, which can be replaced with a higher-density foam insert for individuals experiencing more rapid or forceful tics.

Additional elements include soft tactile features to provide external sensory feedback, chewable components to support reduction of vocal tics, and removable padded EVA foam inserts. The cotton-lined fleece fabric supports temperature regulation, is machine washable, enhances overall comfort and wearability. Initial focus group feedback has been very positive.



CONCLUSIONS

TRPI are common and significantly affect wellbeing, healthcare use, and participation across rest, productivity, and social domains. Co-designed protective clothing may offer a promising harm-reduction approach that supports safety and occupational engagement without aiming to suppress tics. Further development and evaluation will assess feasibility and effectiveness.

From Training to Practice: Evaluating a CBIT Programme's Impact on Clinician Confidence and Service Pathways

Authors and Affiliations

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BACKGROUND

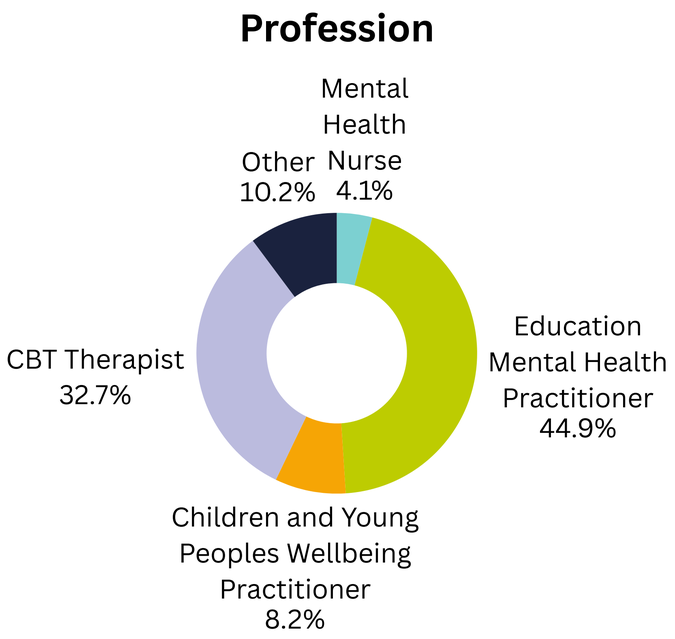
Within the UK, limited access to Comprehensive Behavioural Intervention for Tics (CBIT) remains a barrier to timely and effective treatment for tic disorders, partly due to low clinician confidence, limited training opportunities and inconsistent service provision across regions. Consequently, many individuals with tics and Tourette syndrome experience limited access to evidence-based treatment, long wait times, or are required to travel significant distances to access specialist support. To address these gaps, Tourettes Action developed a structured CBIT training programme designed to improve clinician knowledge, confidence, and readiness to deliver evidence-based tic assessment and intervention within primary and secondary mental health services.

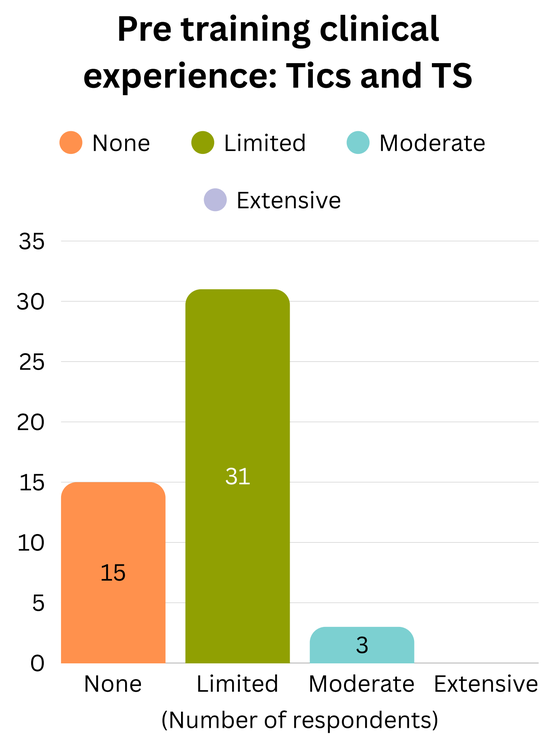
METHODS

A two day CBIT training programme was developed and delivered to Senior Wellbeing Practitioners for Children and Young People PGDip and clinical supervisors at Edge Hill University.

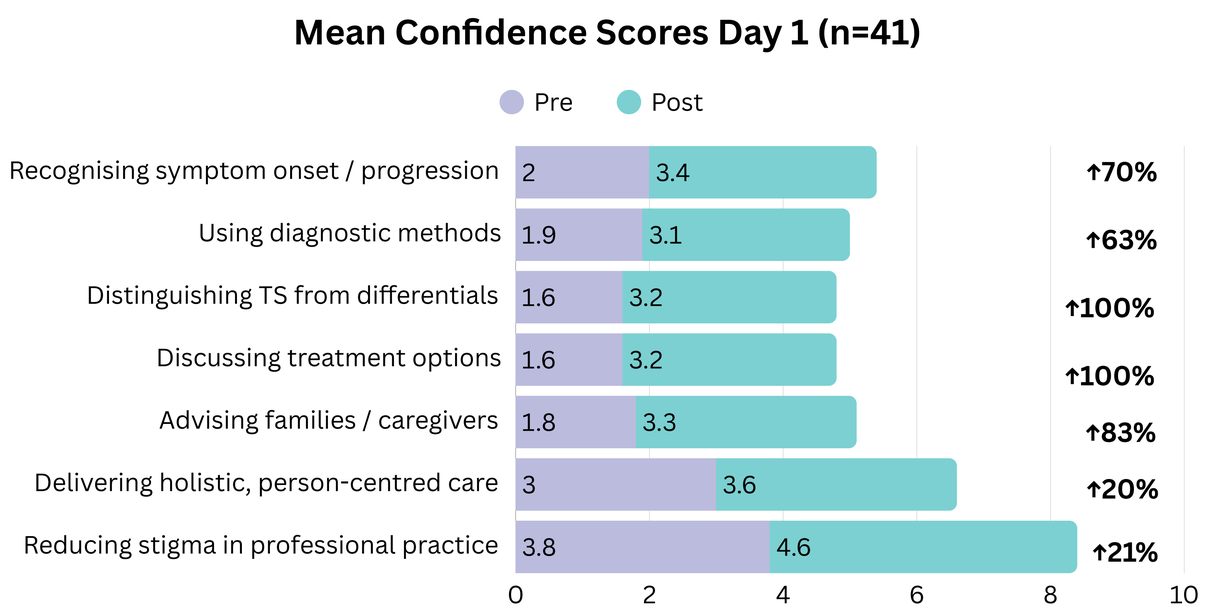
The programme was designed and delivered by Tourettes Action employee, a CBIT-certified Occupational Therapist with lived experience. Pre and Post confidence scores and long term follow up feedback was gathered via a mixed-methods online survey.

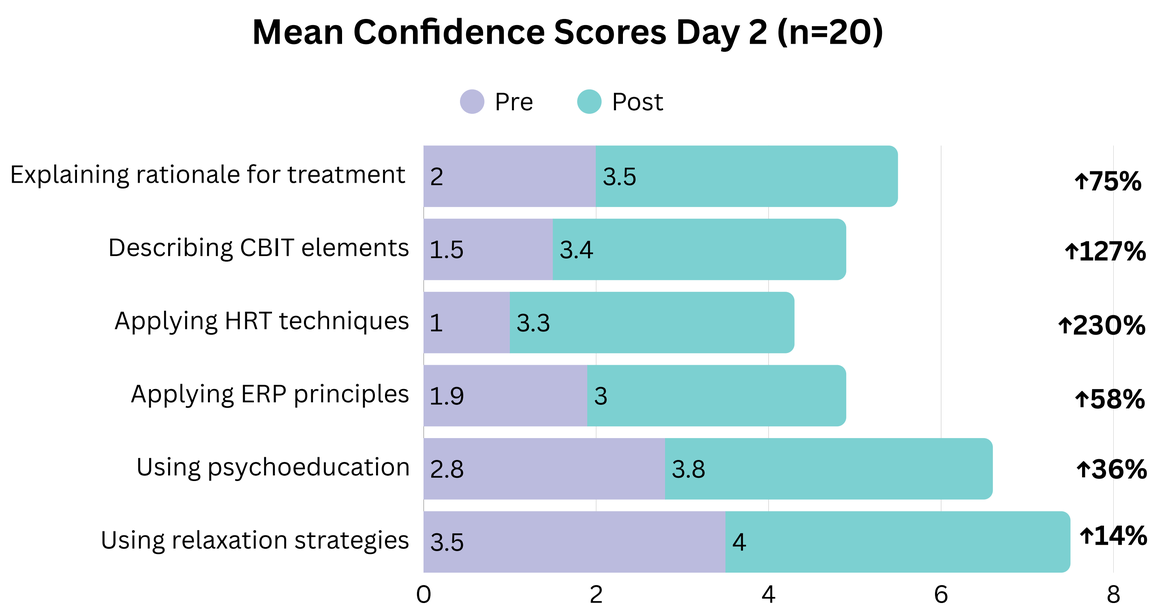
RESULTS





Training Delivery Format	
Day 1: 5 Hours Online	Delivered to students and supervisors; Focused on tic assessment, co-occurring features and differential diagnosis.
Day 2: 5 hours Face-to-face	Delivered to students only and focused on therapeutic interventions including CBIT, Habit Reversal Training (HRT), Psychoeducation, and Exposure and Response Prevention (ERP), alongside practical clinical activities.
Pre, post-and 6 month follow-up	Self-rated confidence scores were collected via mixed method online surveys. Qualitative data from open-ended responses were analysed thematically.





Qualitative survey analysis (n=61)		
Specialist Expertise & Lived Experience	**Improved Clinical Understanding**	**Demand for Further Training**
• Expertise valued • Lived experience enhanced learning • Real-world examples and case studies	• Better understanding of tics • Differential diagnosis • CBIT and alternative interventions	• Longer sessions requested • More discussion time • Practical skill development
• "The knowledge, skill and expertise of the presenters." • "Videos and your own experiences." • "Very engaging and insightful." • "Accessible teaching approach"	• "Greater understanding of TS." • "Comorbidities and overlap with mental health and neurodevelopmental conditions." • "Difference between tics and functional tics."	• "A lot of information." • "More time for activities." • "Would benefit from longer training." • "More time on ERP would be helpful"

6 Month follow up (n=11)		
55% applied CBIT strategies - those who did not had not had opportunities	**64% supported at least one individual with tics**	**73% shared learning and contributed to tic service development discussions**

CONCLUSIONS

This evaluation demonstrates that a blended CBIT training programme improves clinician confidence and implementation readiness, with early evidence of sustained application. Training may also act as a catalyst for service-level change, supporting development of referral pathways and more inclusive access to care. Programme expansion to a three-day model is planned to support advanced skill consolidation.

When the Body Speaks: An Occupational Therapy–Led Sensory Approach to Tic Management in Tourette syndrome and Functional Neurological Disorder – Case Study

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BACKGROUND

Premonitory urges in Tourette syndrome (TS) are often perceived as uncomfortable interoceptive experiences. Variations in interoceptive sensitivity, characterised by hypo- or hyper-responsivity to internal bodily signals, can impact an individual's ability to recognise and articulate these experiences. This sensitivity also influences the perceived intensity, physical impact, and psychological distress associated with these urges. Consequently, this may hinder participation in traditional tic management strategies, such as Habit Reversal Training (HRT), and increase susceptibility to functional symptoms. Neurodevelopmental conditions, such as TS and the frequently co-occurring Autism Spectrum Conditions (ASC), are linked to differences in sensory domains, including processing, integration, modulation, and reactivity.

METHODS

- Eight-session community paediatrics Occupational Therapy–led intervention
- 15-year-old female who had previously unsuccessful engagement with HRT.
- Diagnoses of TS, Functional Neurological Disorder (FND) and tic-like behaviours and was awaiting an ASC assessment.
- Presented with severe motor and vocal tics (YGTSS = 86), coprolalia, non-epileptic seizures, alexithymia, and significant sensory sensitivities, contributing to reduced school attendance (61%).

INTERVENTION

ASSESSMENT
- Getting to know you/ LEGO games
- Administration of YGSSTS

ASSESSMENT / GOALS
- Occupational Therapy interview
- Goal setting
- Adult/Adolescent Sensory History (AASH) self-report and parent/carer

PSYCHOEDUCATION
- Face-to-face psycoeducation for young person, parents, and siblings

SCHOOL CONSULTATION
- 1:1 online meeting with SENCO and Head of Year, staff training on TS, functional tics and FND, including attention, arousal, and sensory influences
- Support and response plan, use of ABC charts to monitor symptoms and FTLB

SENSORY INTERVENTION
- Review of assessment outcomes and sensory psychoeducation
- Tactile / auditory modulation strategies

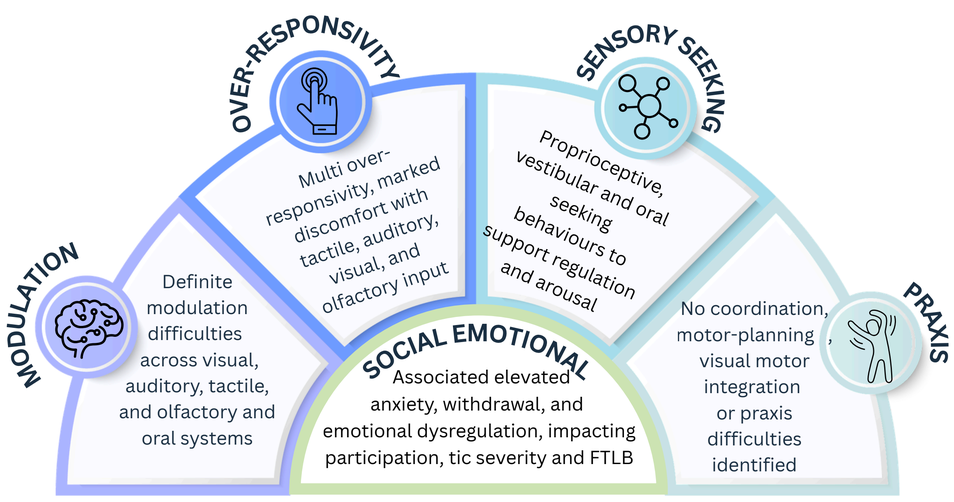
SENSORY INTERVENTION
- Interoceptive awareness training to build recognition of premonitory urge, bathroom cues, and stress signals

SENSORY INTERVENTION
- Proprioceptive and vestibular input for regulation
- Sensory attention reorientation strategies

SENSORY INTERVENTION
- Individualised sensory regulation ladder
- Re-administration of YGTSS

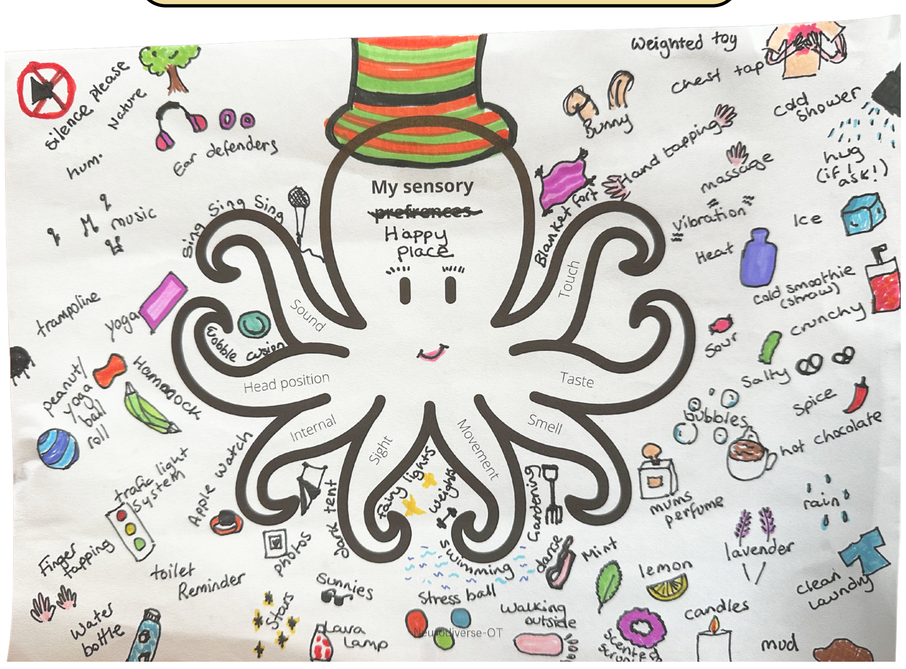
REVIEW / GOALS / FEEDBACK
- Four-week post-intervention telephone review and GBOS outcome measures and digital feedback forms

Adult/Adolescent Sensory History outcomes



Goals	Confidence
I want to better understand my tics	2/10
I want to better manage my tics	3/10

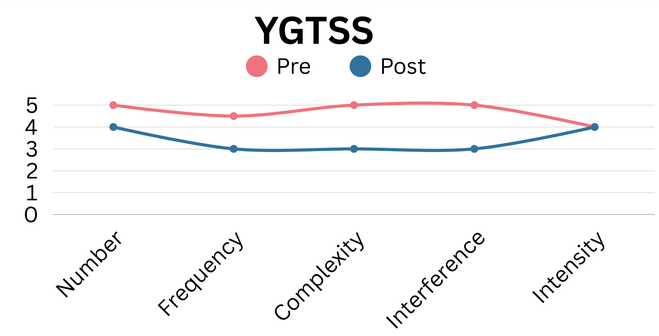
Personal Sensory Supports

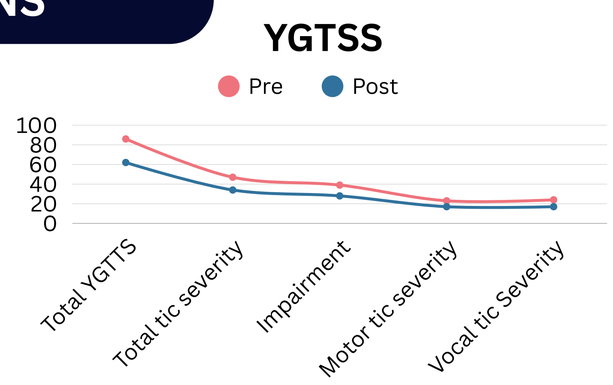


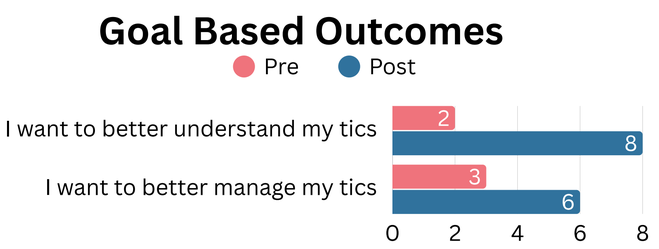
Sensory Modulation Ladder

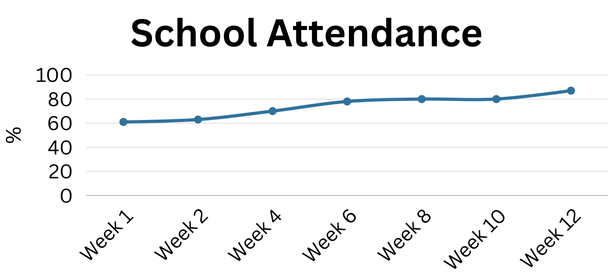
What I feel	What you might see	What I need
Shut down Overwhelmed Fight Flight Freeze Anger Hot Too much!	• Self-Hitting • Punching objects • Screaming or shouting • Head banging • Picking my skin/scratching • Panic attacks • Agitated • Non verbal • Non-epileptic seizures • 'Tic attacks' • Throwing objects • Big tics • Complex tics • Breaking my own and other people's things • Not attending school or social activities	• Ice • Timed tapping, fingers, chest • Butterfly hug • Privacy from others • Low demand setting • Reduce external stimuli • Environmental I spy game • No background noise • Scented scrunchie (mums perfume) • Time in dark tent with fairy lights • Vibrating pillow squeeze and breathe • Weighted soft toy • Slow rocking motions • Time in my body sock - alone
Overstimulated Irritated Fizzy Short fuse Unfocused Restless Unheard	• Agitated • Touching objects • Touching other people • Covering my ears • 'Snappy' or 'Sassy' • Pacing my room • Lots of tics • Swearing tics • Difficulty suppressing my tics • Not attending school but still attending social activities	• A new environment • Crunchy, salty, or sour snack • My 'Chill Winston' playlist • Deep pressure on my hands - self massage/pressure points • Fresh air/time outside to walk and run • Scented oil - lavender, jasmine and orange • Slow rocking motions • Roll body on exercise ball • Body weight exercise - wall sits, weights, resistance band, swim
Calm Focused Alert At my best In my wise mind Ready to rock Ninja mode	• Engaging with people • Being my best fun self • Spending time with others • Doing my activities • Attending school • Eye tics • Mouth tics • Nose clearing tics • Steady tic severity • Using my fidget toys • Humming • Asking other people questions • In communal areas in the house and school • Attending school and social activities/dance	• Regular movement breaks • Timed finger tapping • Fidgets • Music in the background • Wobble cushion • Resistance band on my chair • Controlled sounds • In ear noise reducing head phones • Digital and physical prompts to eat/drink • Time outside • Barefoot nature walking • Reminders of my long term goal • Praise and positive feedback • Visual feelings check in
Under-stimulated Sloth mode Tired Unmotivated Can't be bothered Hopeless Bored	• Slow • Sleepy • In bed • No energy • Low mood / tearful • Spaced out • Low motivation • Can't be bothered • Quiet talking • Barely any tics • Heavy and sore • Not attending school or social activities or dance	• 'Morning madness' playlist • Cold drink - smoothie or iced coffee • Shower • Lemon / mint body wash • Bouncing or spinning • 'Dance it out' • Spiked massage ball on feet • Walk on the textured mat • Sorting games • Lego • Cold air / time outside • Bare foot nature walking

OUTCOMES / CONCLUSIONS









- Reduced frequency and duration of non-epileptic seizures
- Improved confidence and consistency in managing tic and FND symptoms for parents and school staff
- Tic severity decreased (YGTSS: 86–62), notably in impairment, frequency, and complexity
- Greater engagement with sensory-based supports, reported to be more enjoyable and less distressing than previous HRT attempts
- Enhanced awareness of premonitory urges, reduced tic-related distress, better arousal regulation, and increased participation in activities
- Highlights the potential benefits of sensory-informed methods combining interoceptive awareness with sensory modulation and attention-based strategies to reduce tic and functional symptomatology