

Design and Pilot Study of an Occupational Therapy-Led Employment Advocacy Intervention for Adults with Tourette syndrome

Authors and Affiliations

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INTRODUCTION

Tourette syndrome (TS) in adulthood is associated with employment challenges, particularly in individuals with severe tics, coprolalia, and certain co-occurring conditions. Tourette's Action (TA), a UK charity supporting people with TS, offers advocacy to adults via their occupational therapy (OT)-led Therapies and Advocacy service. This abstract outlines the development and pilot testing of an OT-led Employment Advocacy Intervention (OT-EAI) designed to support employees with TS and their employers. The OT-EAI was developed collaboratively with key stakeholders, including the charity's lived experience advisory panel.

METHODOLOGY

Pilot testing: 3 employees and their employers

Employment settings			Years in service			Years since dx			Team size		
University	NHS	Charity	1	7	3	4	15	9	30	200	45

- Universal downloadable employee and employer guides at start of OT-EAI
- 2-7 Targeted online interventions: Individual TS psychoeducation, personalised RA, sensory recommendations, executive function strategies.
- Specialist online whole team training: Attended by the employee, colleagues, HR and manager.
- Mixed Method non-standardised feedback questionnaire post OT-EAI

OT-EAI

EMPLOYEE	EMPLOYER
	
Guide includes: steps to employment, interviews, employment law, reasonable adjustments (RA), managing stress, case studies, signposting.	

OT-EAI TARGETED RECOMMENDATIONS	TASK:	Break down large tasks into chunks	Use a strengths based approach	Set flexible targets	Executive function strategies	Regularly review needs
	PHYSICAL ENVIRONMENT:	Sensory modifications	Private space to tic	Hybrid working	Adaptive equipment	Building design and access
SOCIAL ENVIRONMENT:	Whole team training on TS	Support to inform customers	Support to inform colleagues	Robust Equality and Diversity policy	Create a culture of acceptance	

ONLINE TEAM TRAINING

- Intro to TS
- Contributing factors
- Co-occurring conditions
- TS impact on daily living
- TS in the workplace
- How you can support people with TS
- Reasonable adjustments
- Case studies
- Myth busting
- Support from TA



RESULTS

Figure 1: Employer confidence supporting employee pre and post OT-EAI (0-5 scale)

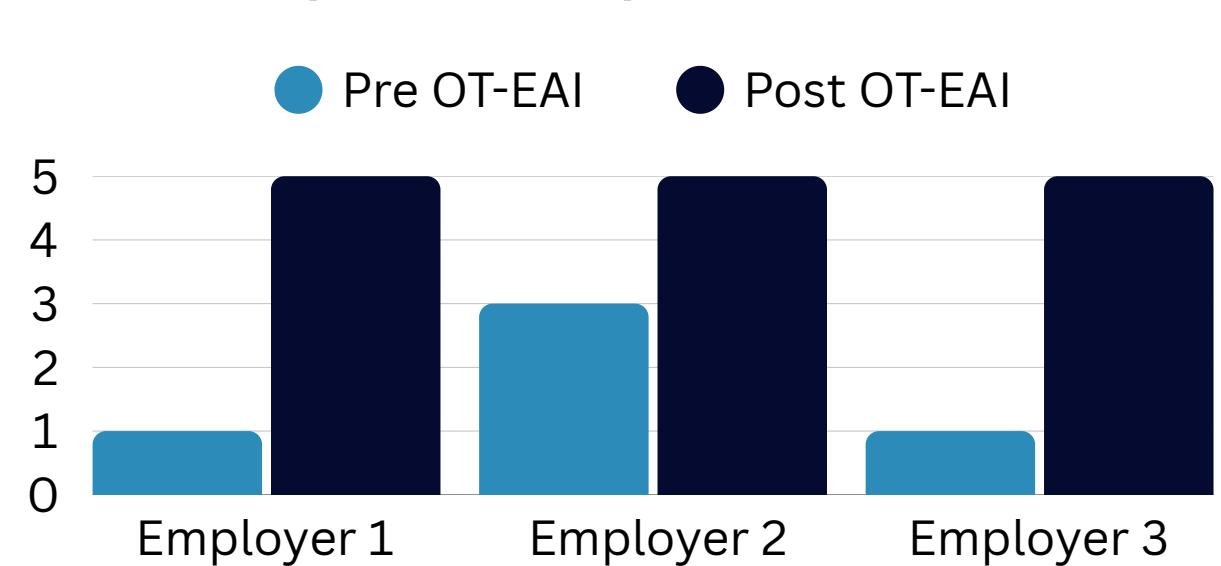


Figure 2: Employee confidence disclosing condition pre and post OT-EAI (0-5 scale)

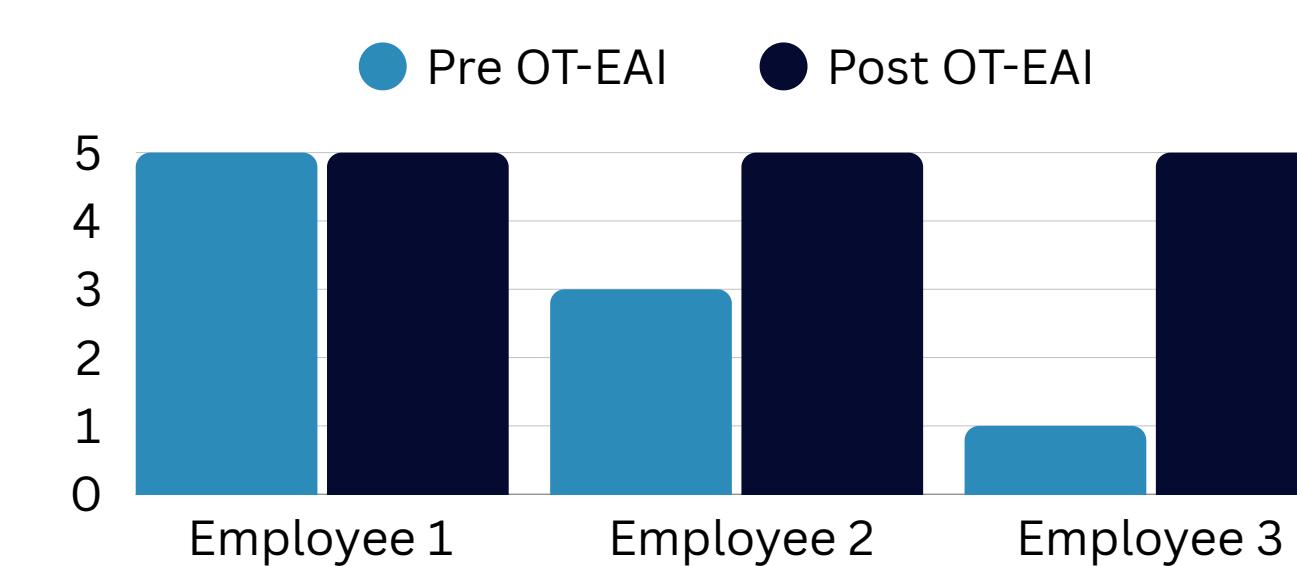


Figure 3: Employee workplace wellbeing and tic impact likert scale post OT-EAI

Since accessing the OT-EAI...	Strongly Disagree	Disagree	Neutral	Agree	Strongly agree
I feel better supported in the workplace				I	II
My working relationships have improved				I	II
I better manage my TS in the workplace					III
My focus and performance have improved			I		II
My employer has implemented the recommended RA					III
I feel safer to tic in work				I	II
My tics have reduced			II	I	
I feel less distressed by my tics				III	
Others respond less to my tics			I	I	I
I suppress my tics more in work	III				
I better understand my neurodiverse strengths					III
I better understand my sensory needs				I	II

Figure 4: Employer feedback on 1:1 targeted support calls

- "The calls provided a vital space to explore the individual needs of our employee"
- "We implemented the recommended adjustments across the whole service which have benefited the whole team"
- "I now know how to respond to, and support their tics, I feel more confident in having conversations about TS and workplace performance"
- "Such simple strategies have made such a big difference performance is improved, we have had less conflicts and misunderstandings"
- "I am more mindful of being aware of my colleagues triggers and my role in helping to manage these"
- "We thought about where any anxieties or symptoms would have the most impact and developed strategies to resolve those"
- "The 121 sessions were most helpful as a manager but the training helped our employee to feel more understood by other members of the team"

Figure 5: Employer feedback on team training:

"It really helped us understand where we could have the most positive impact and where harm could be caused. It helped everyone be more comfortable talking about the condition which helped us be more considerate and open with our staff member. It also meant that staff member didn't have to waste their energy or have an obligation to educate people about their condition either which I think is important"

CONCLUSION

The OT-EAI was developed to offer a stepped model of support, offering accessible universal resources and brief targeted online intervention, in conjunction with adapting the broader social environment through specialist team training. The primary goal of OT-EAI is to reduce social, physical, sensory, procedural, and environmental barriers to accessing and remaining in meaningful employment for adults with TS.

Pilot findings highlight the positive impact of OT-EAI at both individual and service-wide levels, across diverse settings. The project outcomes will inform the development of the TA TS Employment Passport, a co-produced personalisable resource, that aims to bridge the gap between universal and targeted support, offering a more sustainable approach to OT-EAI. Future research should capture long-term outcomes, utilise standardised outcome measures, and draw upon a larger sample size.