



Interim Summary: How effectively are Neurodivergent Women supported in the workplace?

A spotlight on: Tourette Syndrome.

Talking about ticc-ing at work

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Introduction

Awareness about neurodiversity in women is growing, but there is still much work to be done.

Disabled women represent the largest group of unemployed people who want to be working. The disability employment gap is largest for disabled women aged 45 to 49 years and 55 to 59 years (Office for National Statistics, 2021).

It is essential for equality and diversity in employment that the important intersecting aspects of gender and disability are addressed. Neurodivergent women encounter intersecting gendered and disabling barriers which may create a 'double disadvantage' (Nagib & Wilton, 2020) for their employment.

This is increasingly documented in relation to aspects of neurodiversity such as autism. But there is currently a lack of accessible research-informed material available about Tourette Syndrome and women.

This interim summary of research conducted by Dr Gemma North shines a light on workplace practice in relation to Tourette Syndrome and ticc-ing at work.

More than [300,000 children and adults](#) in the UK have a diagnosis of Tourette Syndrome. Tics are often a symptom of Tourette Syndrome. Tics may present as involuntary motor movements – a jerk of the head or neck, for example – or as vocalisations including throat clearing or using certain words and phrases. There is a buildup of tension behind a tic that is often relieved by expressing it.

Tics are thought more likely to increase in adulthood for females.

This summary explores some of the barriers and enablers women with Tourette Syndrome encounter at work and discusses how neuro-inclusion in employment benefits everyone.

Research Methods

In 2022 with the support of [Tourette Action](#) and other agencies including [Assert](#) for Autistic Adults, [ADHD Aware](#), and [Diversity and Ability](#) participants were recruited. This research project could not have been carried out without the generous contributions of partner agencies and the participants who shared their lived experiences.

The research complied with ethical procedures of the University of Sussex and associated partner organisations.

89 participants took part in the survey and shared their experiences of being employed as (self) identifying neurodivergent women. Of these 89 participants, 23 women identified as having Tourette Syndrome (21 diagnosed, 2 self-diagnosed). It was common for participants to report more than one type of neurodiversity (14 of the 23 women with Tourette Syndrome also had a diagnosis of a different neurodiversity).

The survey aimed to:

- i) Collect demographic information about neurodivergent women.
- ii) Gather data about employment and working practices of this group, with some attention given to the impact of the Covid-19 pandemic.

12 neurodivergent interviewees participated in Semi Structured interviews. 4 of these were women with Tourette Syndrome. These aimed to:

- i) Gather in-depth information about neurodivergent women's experiences at work.
- ii) Understand what is working well for them and where there is space for improved support.

A thematic analysis was carried out on the transcribed interview data. These six initial themes emerged from the research data:

- disclosure
- (un)masking
- belonging
- workplace support
- impact of the pandemic
- changes

A focus on Tourette Syndrome

Interviews with women with Tourette Syndrome explored whether they talked to other people at work or in place of study about their neurodiversity. This question evoked a wide range of discussion. In this summary the key themes of **disclosure**, **(un)masking** and **workplace support** are explored.

Summary of Contextualising Information: Talking About it

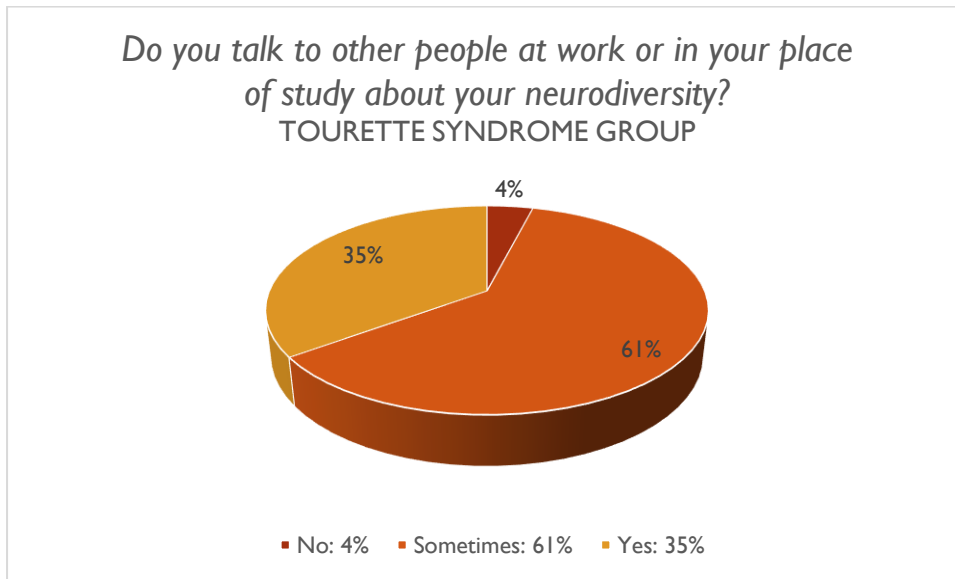
The survey participants who said Tourette Syndrome was part of their neurodivergent identity described their challenges at work. Although the majority told us they *'sometimes'* talked about the nature of their Tourette Syndrome at work, they often found themselves hiding or masking their tics.

Most survey participants with Tourette Syndrome (61%) said they *'sometimes'* talked about their neurodiversity with colleagues at work.

Comments included *'It is mentioned, when necessary, but not otherwise to avoid judgement'* (Survey Participant 64).

Comments from the 35% who said *'yes'*, they talked to colleagues at work about their Tourette Syndrome included *'I have told the majority of people I closely work with. I can suppress; however, this can be very distracting and exhausting'* (Survey Participant 52).

The person who did not talk about it at all (1 person) said *'I always try my best to suppress my tics - I am in the process of getting a formal diagnosis'* (Survey Participant 75).



n=23

Disclosure

Many research participants said they needed more space and understanding from co-workers to feel comfortable about telling them about their tics.

One interviewee called Riley*, was diagnosed with Tourette syndrome in early childhood. Riley chose not to explain the nature of it at work because:

'It would have affected, first of all, if I was employed, but also second of all what I would have been allowed to get involved in due to some serious lack of understanding about the condition.'

When a person finds themselves hiding how they feel or suppressing who they are to fit in at work, they could be described as performing extra “emotional labour” ‘according to institutional rules and customs’ (Hochschild, 2012: 49).

Neurodivergent women often feel the pressure to cause minimal inconvenience to others (North, 2021). The fear of ‘scrutiny from others’ (Coleman & Melia, 2023: 17) along with the practice of doing extra unacknowledged work to disguise tics can have a significant impact on the wellbeing of women with Tourette Syndrome at work. While this is exhausting, unmasking tics can feel risky.

(Un)Masking

There were however examples in the research of participants experiencing positive responses to unmasking and simply being themselves at work.

Another interviewee, Kimberly*, is employed in very different circumstances to Riley. She is a member of a team with other openly neurodivergent people whom she describes as accepting of difference.

Kimberly does not usually have to suppress a 'tic attack' at work. Tics can emerge or retreat at different points in life. For example, Kimberly has recently developed a tic in her ankle which resembles a kick, so Kimberly shared this 'new' one with her colleagues in the team's WhatsApp group.

Workplace Support

Responses from those participants with Tourette Syndrome indicated that they would like to see changes in their workplaces.

Flexibility in working practices which include opportunities to work from home where possible were indicated as important in enabling people to avoid sensory overload and to take rest breaks when they need to. This aligns with other recent workplace research findings such as that carried out by The Work Foundation which found that following a shift in working practices after Covid-19 pandemic restrictions '70% of disabled workers said that if their employer did not allow them to work remotely, it would negatively impact their physical or mental health' (Taylor, et al., 2022: 13).

The research indicated that many workplaces do not have the necessary support in place to help employees with Tourette Syndrome feel comfortable. Masking a symptom like a tic can be exhausting, but unmasking it in front of work colleagues also feels extremely daunting.

Words such as 'Acceptance' (Survey Participant 54) were used to explain the desirable qualities of valued colleagues. Colleagues who appreciate that neurodivergent people do not necessarily 'work the same way as everyone else' (Survey Participant 54) were an important factor in our respondents feeling comfortable at work.

Neurodivergent people may bring a different approach to completing their work task. One survey participant commented that it 'Would be nice to be open about needs without being concerned that I would be treated differently, or be less valued' (Survey Participant 64). A shift in cultural expectations of what constitutes good work is required. A focus on the strengths and the skills individuals bring to the job instead of how they go about achieving their tasks is an example of such a shift. Strengths such as creativity, innovation, and focus are common in neurodivergent people and these 'need to be harnessed and supported' (McDowall et al., 2023: 46).

The attitude of employers was one of the most meaningful qualities identified by participants. One of the survey respondents with ADHD said the key to their comfort at work was 'support with understanding and zero judgement' (Survey Participant 35).

Findings: 'Be myself'

Sometimes people are so accustomed to masking that they carry on doing it unless they can no longer suppress their tics. Having no choice but to be themselves, the tics can become a 'talking point' (Survey Participant 83). This participant said 'I have found talking about it makes everyone, including myself, more comfortable' (Survey Participant 83).

Asking employers for workplace adjustments or to change their ways of thinking about Tourette Syndrome and other aspects of neurodiversity may not be well received. This is partly because employers can be fearful of changes. Those who ask for help may be regarded as an inconvenience.

However much recent research into workplace productivity and employee retention suggests that making positive changes are usually cost-effective and can benefit everyone including disabled and neurodivergent people. 'Flexible and hybrid working, as well as sensory-friendly environments tailored to need' (McDowall et al., 2023: 46) increase the likelihood of employee loyalty. These provisions are good practice when taking steps to providing neuro-inclusive workplaces.

In conclusion

This summary has been a glimpse into the lives of neurodivergent women at work with a particular focus on Tourette Syndrome.

It is difficult to draw broad conclusions from such a small-scale study. The themes do however align with the findings of other recent workplace research relating to disability and workplace practices (E.g. Taylor, et al., 2022; McDowall et al., 2023). The small scale and qualitative nature of the research allows for the emergence of the unique lived experiences of neurodivergent women in the context of broader workplace practices.

Our traits make up who we are and they are important in the workplace. There are multiple protected characteristics explored in the wider study which include sex, gender, age, and disability. Future research will explore the intersection of these various aspects of identity in greater depth.

'Successful inclusion leads to feelings of belonging' (Smith and Kirby, 2021: 223). The key 'take away' message from this work is the need for employers to encourage discussions about neurodiversity and for attitudes to keep evolving. Neuro-inclusive cultures benefit everyone.

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*Identifying characteristics such as names have been changed to maintain confidentiality.

More can be read [here](#) about the experiences of Riley and Kimberly.

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