

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

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

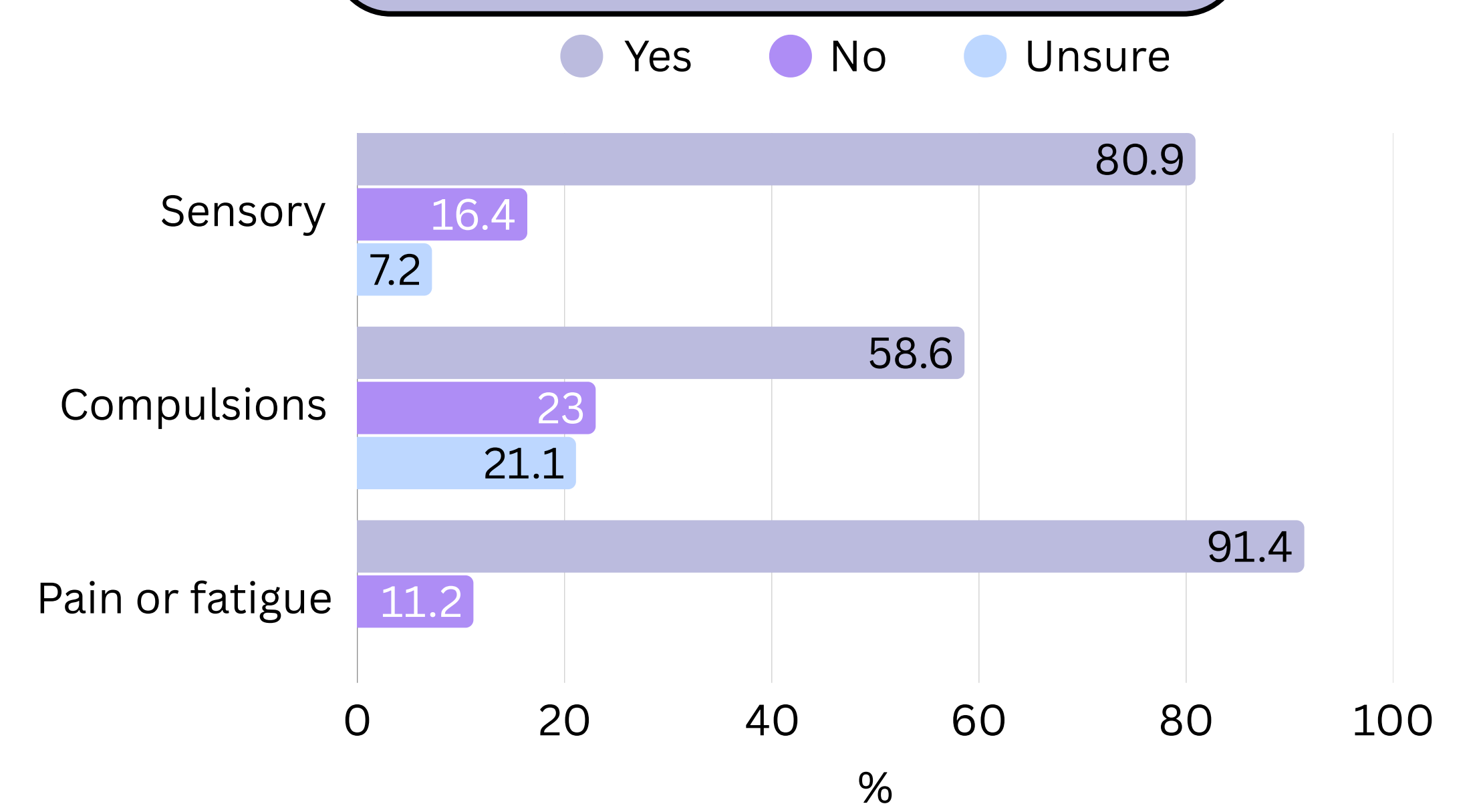
Mean tic impact at work rating

6.3 / 10

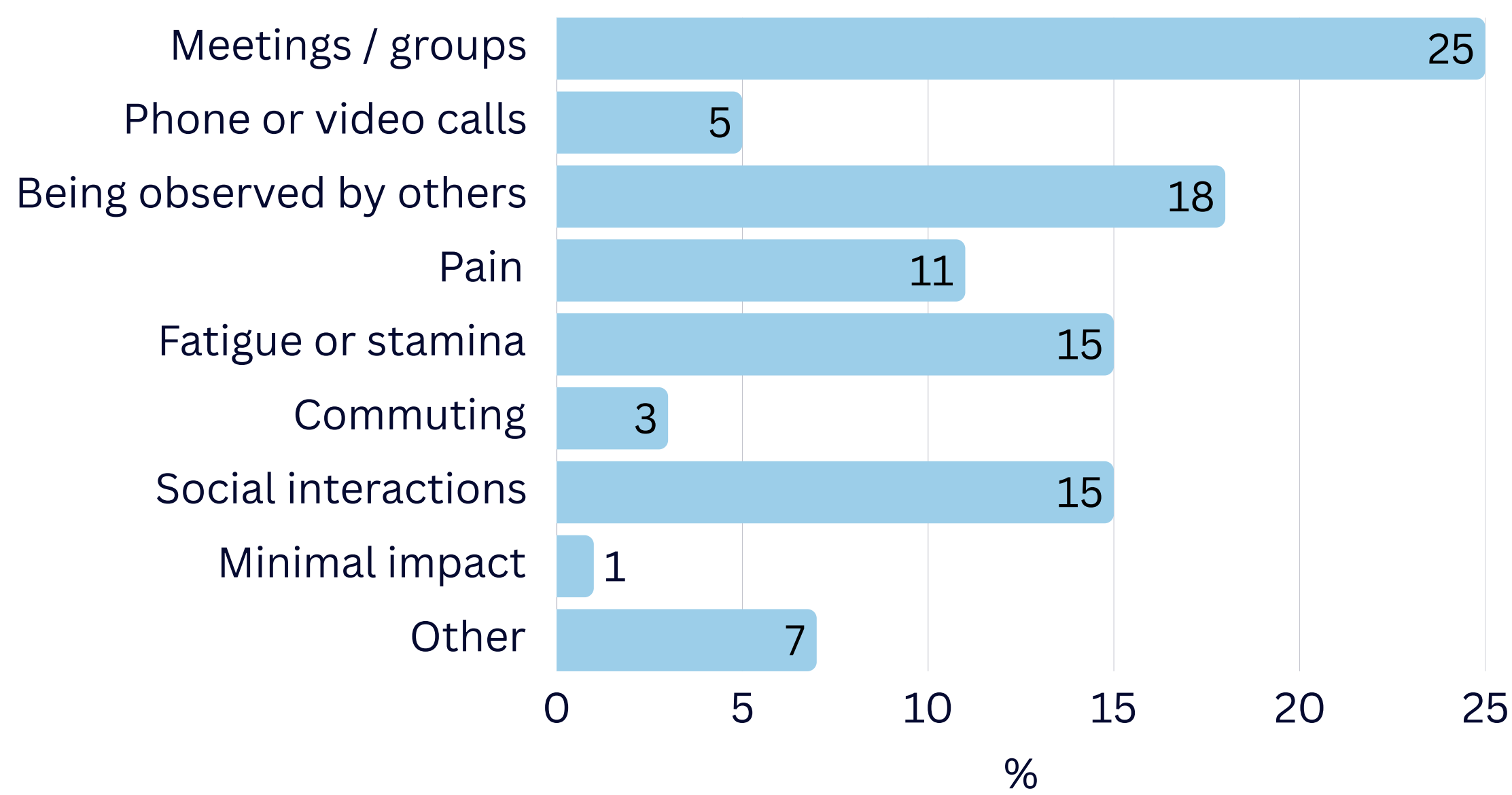
Mean self-reported psychological safety when ticing at work rating

5.29/10

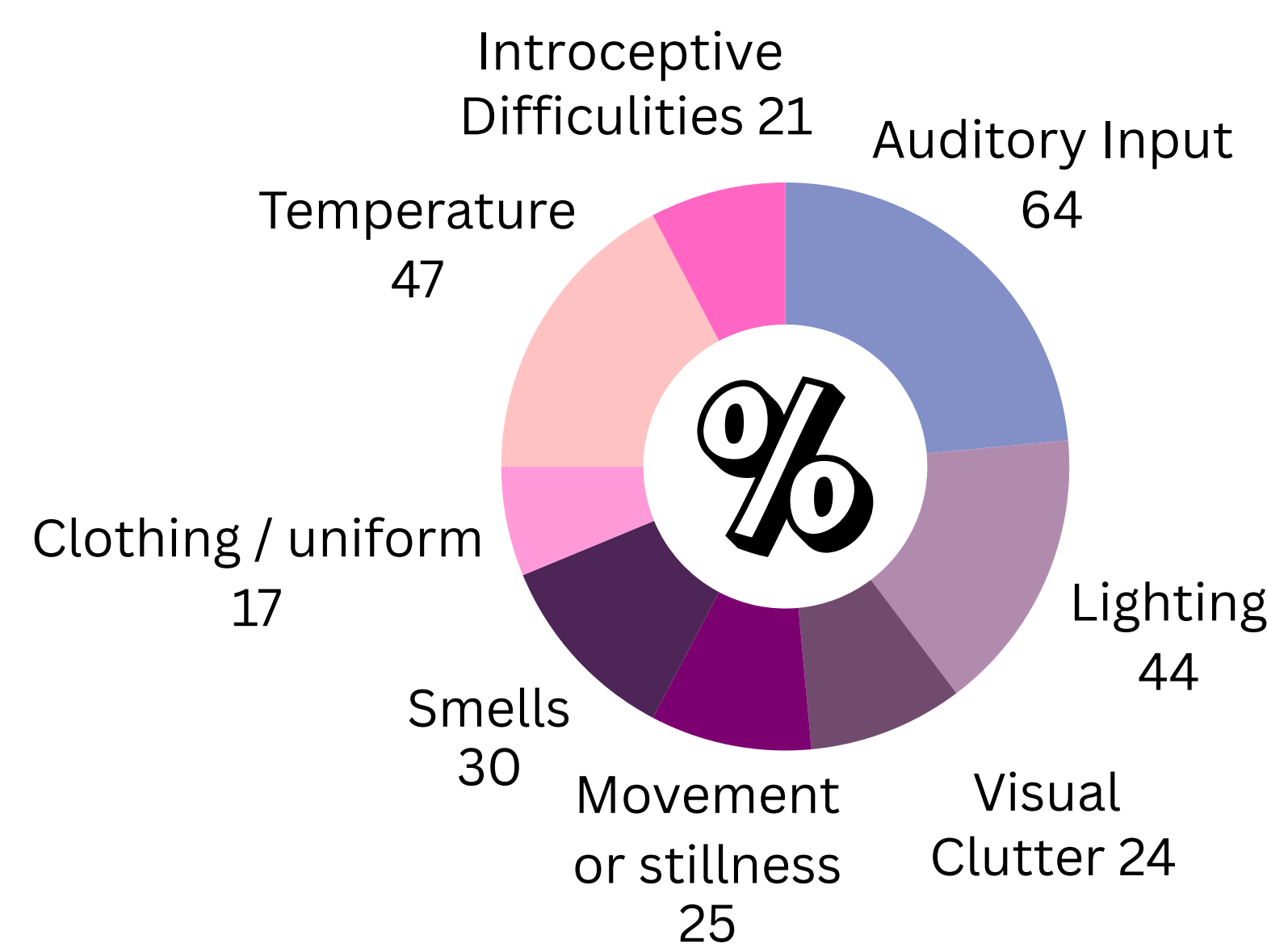
Factors which impact work



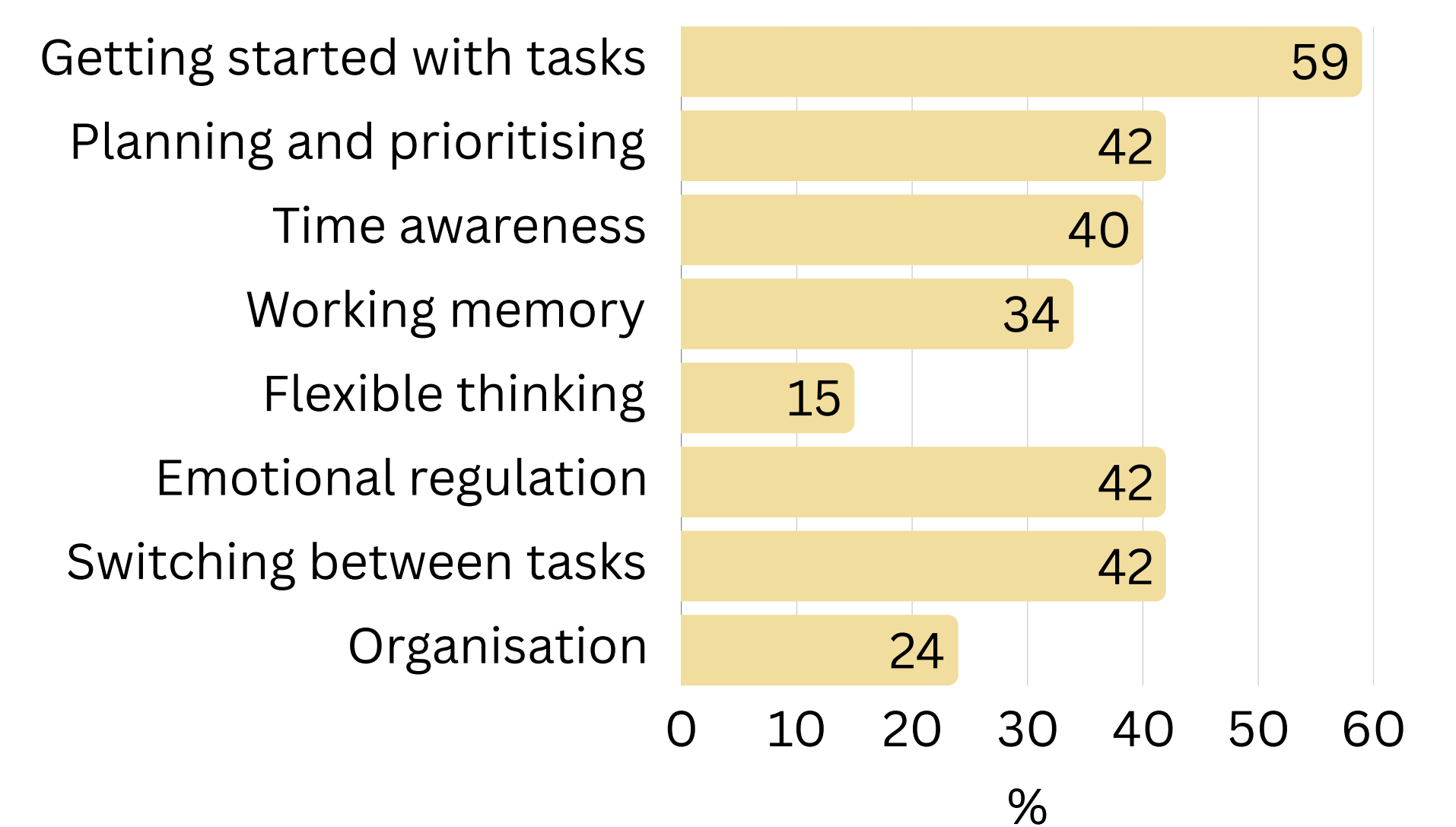
Workplace experiences which impact tics



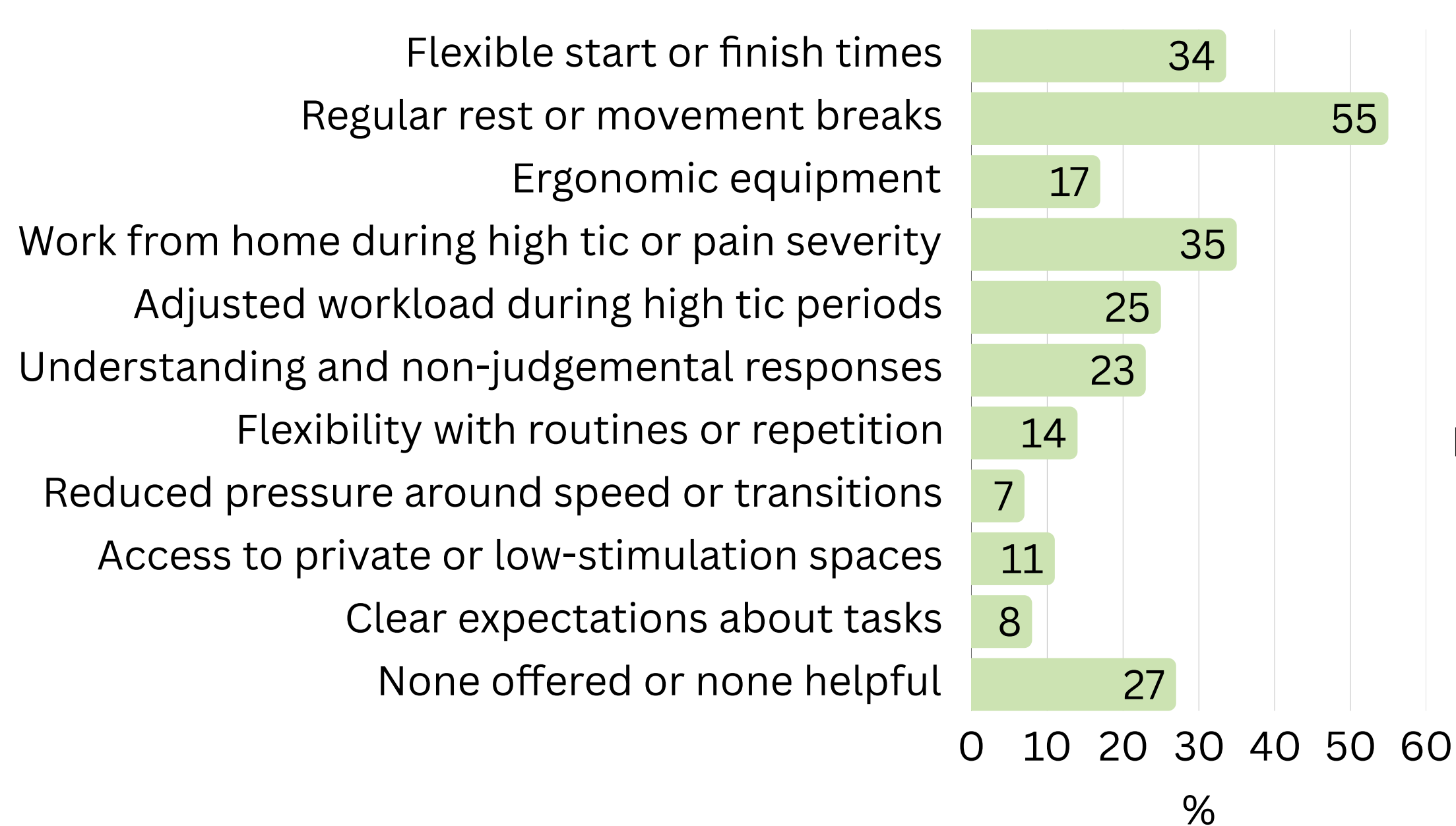
Sensory experiences which impact work



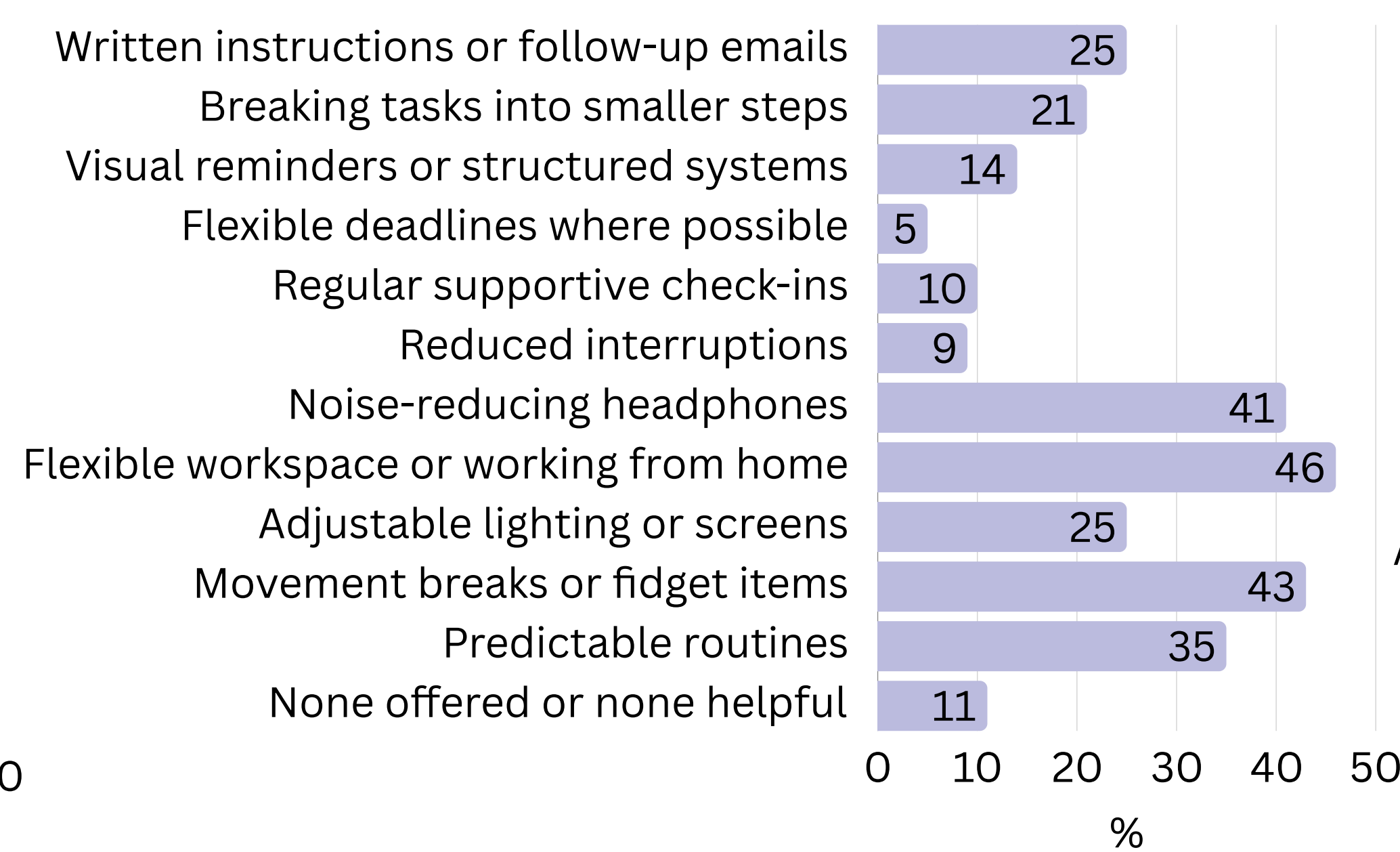
Executive Function needs which impact work



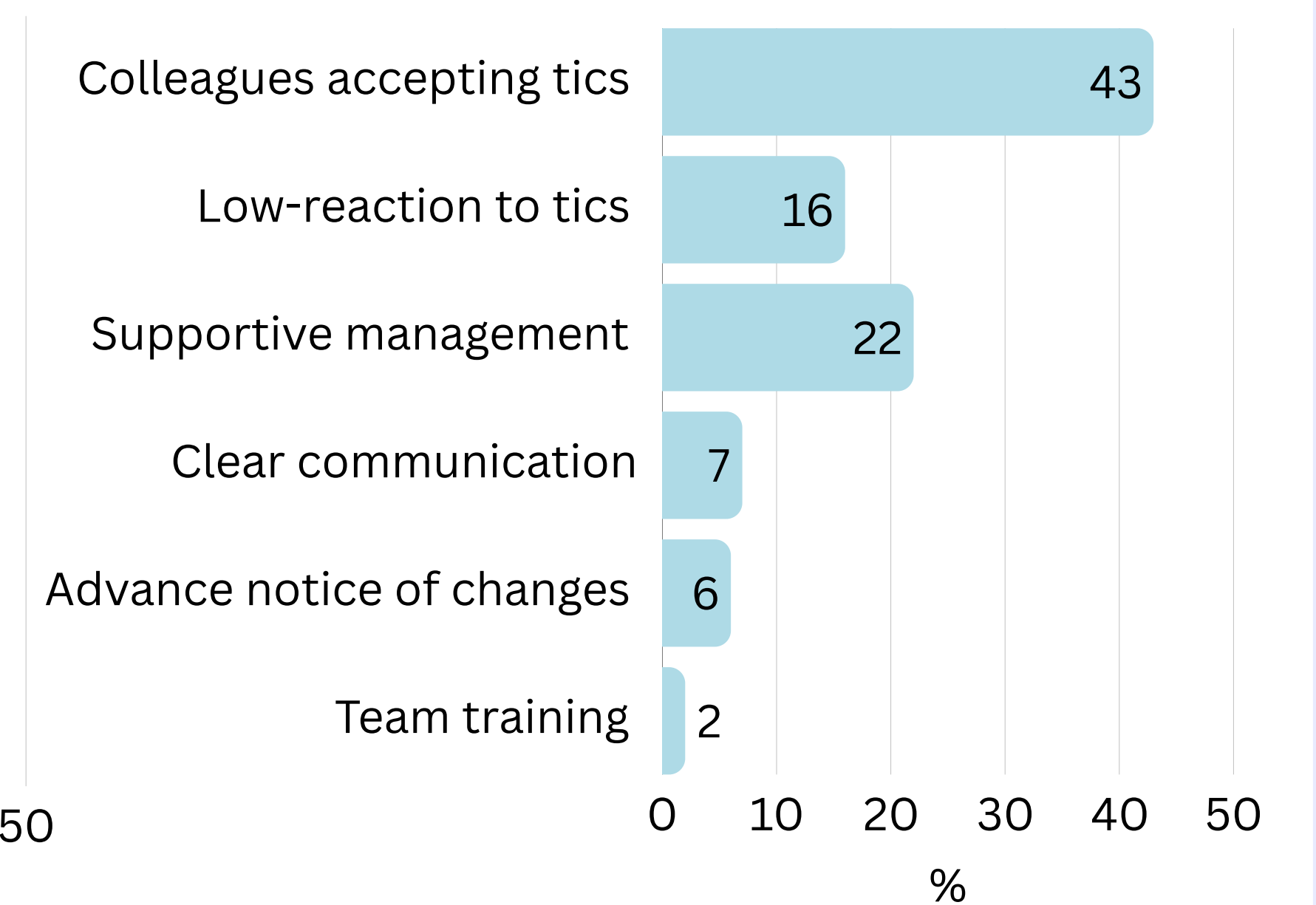
Helpful workplace task and process adjustments



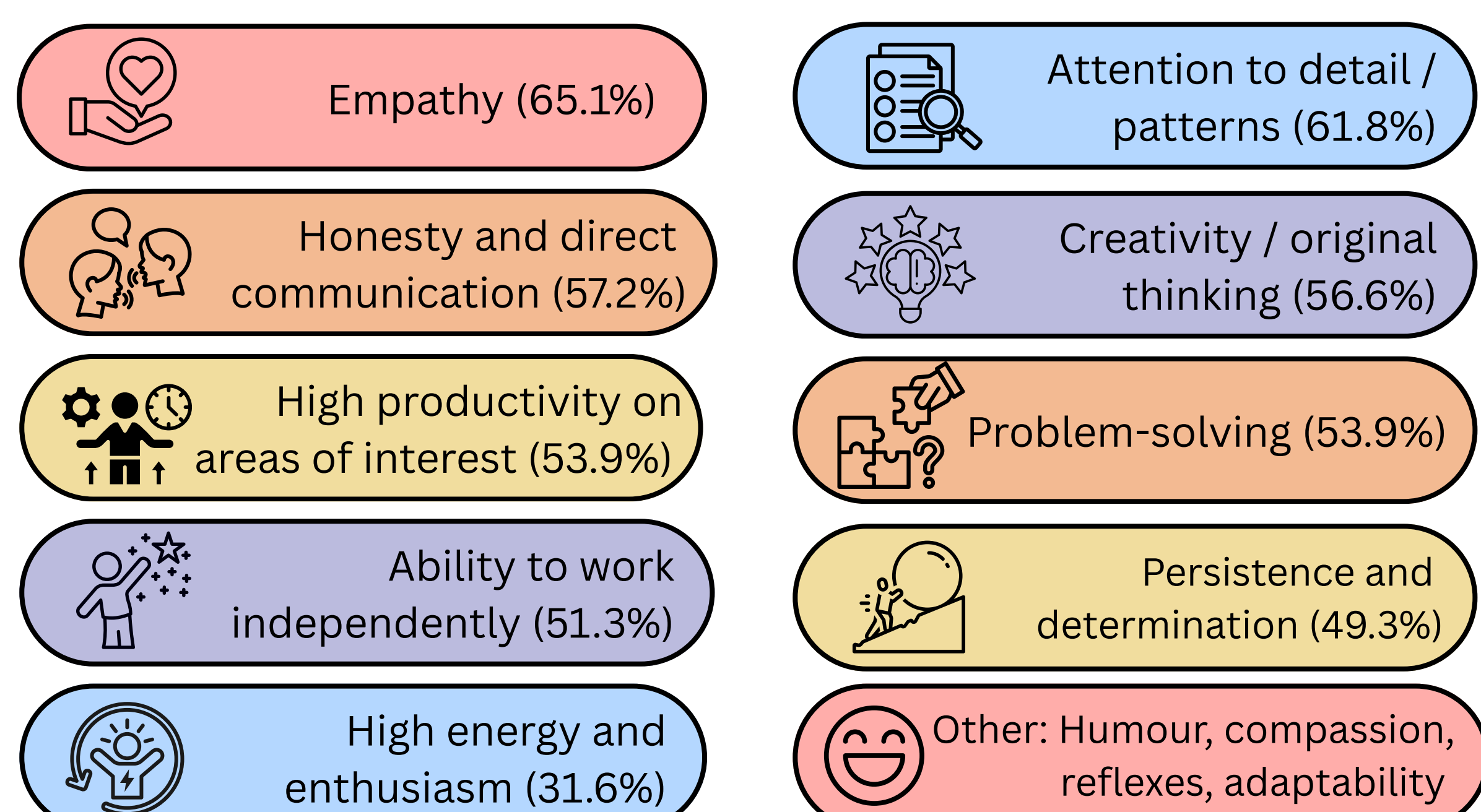
Helpful Executive Function and Sensory Adjustments



Protective workplace factors



Workplace strengths and skills (n=152)



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.