

## BACKGROUND

- Language surrounding autistic people's repetitive movements such as hand-flapping and body-rocking is often pejorative, and treatments to control them remain popular despite a lack of strong evidence of efficacy or ethics.<sup>2</sup>
- Autistic people have reclaimed these so-called "self-stimulatory behaviours" as "stimming"; neurodiversity activists say stimming helps them cope or communicate and oppose attempts to eliminate non-injurious stims.<sup>3,4</sup>
- A pilot study reported autistic adults stim for a various reasons (e.g. to reduce anxiety or overstimulation) and usually enjoy it.<sup>5</sup>
- Yet no in-depth study has examined stimming from the perspective of autistic people, and the topic remains contentious and poorly understood.

## STUDY AIMS

To examine autistic adults':

- Understanding of repetitive "stimming" behaviours
- Perceptions of why they stim
- Views on the value, if any, of such behaviours

## METHOD

- Autistic adults ( $n = 31$ ; ages 21-56; 20 men, 10 women, 1 non-binary) were recruited from the networks (e.g., a residential home and training centre for autistic adults) of research teams in Southwest England and London.
- Participants either took part in individual interviews ( $n = 19$ ) or focus groups ( $n = 12$ ,  $n = 6$  per group), which used the same semi-structured interview schedule.
- The richer interviews and more systematic focus groups provided complementary data and were analysed together.
- Data were analysed thematically<sup>6</sup>, which involved detailed reading and note-taking, developing a coding framework organized by the aims and any observed patterns, coding, fitting codes into themes, making a thematic map, and drafting.

## RESULTS: STIMMING AS SELF-REGULATION

- Stimming was identified as a repetitive, usually rhythmic behaviour that commonly expressed through body movements (e.g. "hand-flapping", "feet-flexing", "spinning") but also vocalisations (e.g. "grunting", "stuttering", "singing").
- Many participants said they experienced it as involuntary and unconscious, at least at the beginning of the behaviour.
- No participants consistently and inherently disliked their stims (as opposed to their social consequences).
- Stimming appeared to create a soothing feedback loop that calmed excess emotion caused by "sensory overload" or intense thoughts: "So it just sort of helps quell everything, because you're at the same rhythm with everything." (Luke)

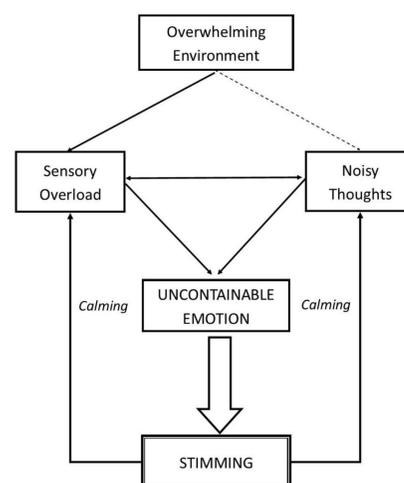


Figure 1. Stimming as a self-regulatory mechanism

- Participants described the cause of stims as either "sensory overload" grounded in an overwhelming environment (e.g. sounds, tastes), or dysregulated, excessive, or distracting thoughts (e.g. traumatic memories, work tasks).
- Sensations seemed more adjustable and avoidable than noisy thoughts: "I've got the environment how I want it and my stress, on the whole now, is more self-inflicted, like having an assignment to do" (Rose).
- Stimming appeared to result directly from emotional hyperarousal, and functioned to calm and communicate: "[s]timming is just a release of any high emotion, so really anxious, really agitated, really happy..." (Rebecca)

## RESULTS: STIMMING (DE)STIGMATISATION

- The second theme concerned (1) the negative reactions that people perceived when stimming, and (2) destigmatisation through acceptance based on understanding of their stims.
- Participants described feeling various resentful emotions when told to stop stimming (e.g. anger, belittlement).
- In response, participants reported trying to repress their stims, through suppressing them in public, transmuting stims into different forms (e.g. Ethan: replacing arm stims with tennis and chess), and concealing stimming from view.
- Although all participants described stims they found inherently helpful, they generally wished to avoid causing harm to others or themselves through stimming.
- They reported stimming becoming less acceptable with age.

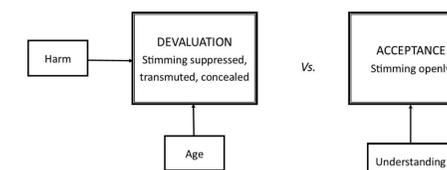


Figure 2. (De)stigmatisation of stimming

- Participants also reported accepting attitudes, because of greater understanding (through others' familiarity with them or their knowledge of autism and the reasons for stimming), which happened more often in private than public.

## CONCLUSIONS

- Stimming is a helpful coping mechanism for many autistic people; social acceptance of non-harmful stims is key.
- Future directions include ascertaining autistic people's perspectives about treating the *causes* of stimming, and comparing stimming with "fidgeting" in non-autistic people.

## REFERENCES

- <sup>1</sup> Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). "People should be allowed to do what they like": Autistic adults' views and experiences of stimming. *Autism*. Advance online publication. doi: 10.1177/1362361319829628.
- <sup>2</sup> Jaswal, V. K., & Akhtar, N. (2018). Being vs. appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences*. Advance online publication. doi: 10.1017/S0140525X18001826
- <sup>3</sup> Bascom, J. (2012). *Loud Hands: Autistic People, Speaking*. Washington, DC: Autistic Press.
- <sup>4</sup> Schaber, A. [gemythest]. (2014, Jan 25) *Ask an Autistic #1 - What is stimming?* [Video file]. Retrieved from <https://www.youtube.com/watch?v=WexCWZPJE6A&t=322s>
- <sup>5</sup> Steward, R. L. (2015). *Repetitive stereotyped behaviour or "stimming": An online survey of 100 people on the autism spectrum*. Poster session presented at the meeting of the International Society for Autism Research, Salt Lake City, UT.
- <sup>6</sup> Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi: 10.1191/1478088706qp063oa