

Is advocacy a choice in academia?: Using Critical Participatory Action Research (CPAR) to explore experiences of autistic academics

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Abstract

For autistic academics, resistance and activism are not strategic choices based on political agenda, but necessary steps to survive. These actions are seen as inherently political only because our very existence is politicized. We explore through mixed media data gathered as part of a CPAR project, how the very act of surviving in academia necessitates a constant negotiation of identity and advocacy.

Full paper

In considering whether HE is 'a place for advocacy and resistance', we first need to understand the concepts of resistance and advocacy, and their implications. Whilst the role that HE plays in societal and economic issues is potentially shifting, within the walls of the ivory tower, a fundamental mismatch between institutional claims of accessibility and the lived experiences of those it aims to support, remains (Mellifont, 2021), and with it, fundamental questions about what it means to 'advocate' and 'resist'.

Methodological Approach:

Here, we present data from a Critical Participatory Action Research (CPAR) project, which includes mixed media data collected in a data bank. The data includes images, videos and free text with the explicit purpose of capturing reflections of those that the project is by and for (autistic academics). In reflecting collaborative design, the research was conducted with a collective of autistic academics, to put forward an exploration of how autistic academics perceive and enact resistance and advocacy within higher education settings that claim to be inclusive yet often perpetuate exclusion. Moreover, we consider the necessity of activism and resistance as survival strategies rather than choices, and the broader implications of these dynamics on HE's role in societal/political issues.

Research Questions:

How do autistic academics navigate and negotiate their identities and advocacy within HE?

What does resistance and advocacy truly mean for autistic academics compelled to navigate these institutional landscapes?

Key Ideas and preliminary findings:

These reflections, framed by a need to clarify what is genuinely meant by 'resistance' and 'advocacy' in this context (whether these are deliberate strategies or forced adaptations to systemic inadequacies), challenge the assumption that resistance and advocacy are choices. For many marginalised people, including autistic academics, resistance and activism are not strategic choices based on political agenda, but necessary steps to survive. These actions are seen as inherently political only because our very existence is politicised (van Stekelenburg et al., 2013; Chapman, 2016). Autistic academics often find themselves involuntarily cast as representatives of autism and disability advocacy—a role that blurs professional identity with personal survival (Botha, 2021).

This research highlights that many institutions remain inaccessible, with EDI initiatives, often designed and implemented by those who do not experience the day-to-day challenges they are designed to address (Tinklin et al., 2004), creating systemic contradictions that necessitate a continuous advocacy that is often unrecognised and uncompensated (Milian & Wijesingha, 2022).

The CPAR data specifically spoke to these points where advocacy was represented through institutional role in advocacy versus the reality of the extent to which these kinds of strategies and initiatives exist or reflect those it says it supports. In addition to the impact advocacy has on autistic academic identity (how we are known and how we know ourselves), the specific tasks and roles that advocacy requires of us, and perhaps most importantly, the cost of being an advocate or not.

Conclusion:

Botha (2021) has previously noted “In my title, I ask “academic, activist, or advocate?”—and my answer is that I am all three. You cannot belong to a community that suffers from violence, marginalization, and suicide and not be. THIS”. This is still reality for many autistic academics. We consider ways to improve this including:

Advocating for a shift from viewing resistance as an optional political act to understanding it as a fundamental aspect of survival and identity affirmation within academia.

Reconceptualization of EDI initiatives, aiming to transform higher education into a space where advocacy is an empowered choice, not a survival necessity.

Critique of the broader institutional practices that affect all marginalised groups within academia.

References

Botha M (2021) Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production. *Front. Psychol.* 12:727542. doi: 10.3389/fpsyg.2021.727542

Chapman, R. (2016). Autism isn't just a medical diagnosis - it's a political identity. [Online]. Available at [Autism Isn't Just A Medical Diagnosis — It's A Political Identity | by Robert Chapman | Medium](#) [Accessed 12/5/24].

Damian Mellifont (2021): Ableist ivory towers: a narrative review informing about the lived experiences of neurodivergent staff in contemporary higher education, *Disability & Society*, DOI: 10.1080/09687599.2021.1965547

Pizarro Milian, R. and Wijesingha, R. (2023), "Why do EDI policies fail? An inhabited institutions perspective", *Equality, Diversity and Inclusion*, Vol. 42 No. 3, pp. 449-464. <https://doi.org/10.1108/EDI-02-2022-0048>

Porta, P. G. Klandermans, & D. McAdam (Eds.), *The Wiley-Blackwell Encyclopedia of Social and Political Movements* (pp. 974-977). Wiley-Blackwell. <https://doi.org/10.1002/9780470674871.wbespm163>

[Rosqvist et al., 2022 Cutting our own keys: New possibilities of neurodivergent storytelling in research DOI: 10.1177/13623613221132107](https://doi.org/10.1177/13623613221132107)

[Tinklin, T., Riddell*, S., & Wilson, A. \(2004\). Policy and provision for disabled students in higher education in Scotland and England: the current state of play. *Studies in Higher Education*, 29\(5\), 637–6](https://doi.org/10.1080/0307507042000261599)

[van Stekelenburg, J., van Leeuwen, A., & van Troost, D. M. M. \(2013\). Politized Identity. In D. A. Snow, D. Della57. *https://doi.org/10.1080/0307507042000261599*](https://doi.org/10.1080/0307507042000261599)