

Autism research and ethics creep

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Autism research and 'ethics creep'

Autism awareness month is often framed around three themes: awareness, acceptance, and inclusion. The merits and limitations of the month itself can be debated elsewhere, but it does provide an opportunity to reflect on how awareness, acceptance, and inclusion operate within research. In particular, autism awareness month offers a moment to consider an issue neuroaffirming researchers regularly encounter that threatens inclusion, challenges acceptance, and reveals a lack of awareness within academic practice. That issue is 'ethics creep' ([Haggerty 2024](#)).

Within autism research and indeed within wider research exploring minority or disadvantaged groups, there is an increasing expectation that researchers engage in participatory or emancipatory frameworks. These approaches challenge traditional research practices in an attempt to address the problematic power imbalance that often exists between researchers and participants ([Bertilsdotter et al 2019](#)). At their core, participatory and emancipatory approaches seek to shift decision-making power away from the researcher and towards participants and their communities. This includes decisions about what should be researched, how research should be conducted, how findings should be analysed and control of dissemination.

The underlying argument is that those most affected by research should have meaningful influence over that research. At a basic level, this helps ensure accessibility and relevance. But at a deeper level, it aims to ensure that research priorities reflect the needs and experiences of the communities involved rather than the interests of researchers alone. In this sense, as I have argued in [my own research](#), participatory approaches aim to move research away from being conducted 'on' communities and towards research conducted 'with' and ultimately research 'by' communities

The most radical form of this shift is emancipatory research, which seeks to place ownership and control of the research process entirely in the hands of those who are typically the subjects of research. However, as [I have argued](#) that within the current academic system, this goal is not fully achievable. One key reason for this limitation lies in the power embedded within institutional ethics processes, and particularly within the phenomenon known as 'ethics creep'.

'Ethics creep' refers to decision making encroachment of ethics committees and policymakers into the research process. Rather than focusing solely on protecting researchers and participants from harm, ethics review processes increasingly influence methodological choices, language, conceptual framing even recruitment and methods design choices. In doing so, ethics boards can inadvertently reduce access, silence communities and result in problematic and sometimes dangerous research.

Two common examples of ethics creep within autism research relate to language and assumptions of vulnerability. First, ethics reviewers frequently require researchers to use person-first language (for example, "person with autism") as a condition of ethical approval. This requirement persists despite a growing body of research indicating that many autistic people prefer identity-first language (for

example, “autistic person”). By imposing a particular linguistic framework, ethics committees may unintentionally silence the preferences of autistic communities themselves.

A second example is the routine classification of autistic people as inherently vulnerable participants. While ethical safeguards are essential, the blanket designation of autistic individuals as vulnerable can reinforce paternalistic assumptions and limit their perceived agency. It also risks contradicting the principles of participatory and emancipatory research, which seek to recognise autistic people as knowledgeable contributors rather than passive subjects.

These examples represent only two of many research decisions that ideally should rest with participant communities themselves. Instead, such decisions are frequently made by individuals who are not members of the communities or cultures being studied.

So how might this be addressed? Ideally, ethics boards could adopt practices similar to those used in some areas of Australian Aboriginal health research where guidelines encourage the inclusion of Aboriginal representatives within the ethics review process. This helps ensure that communities have a degree of oversight regarding research conducted about them and within their communities. In the UK, this might involve universities establishing partnerships with local autism organisations so that autistic voices are represented within ethics discussions and decision-making processes.

Admittedly, developing this kind of structure would require time and resources. Nonetheless, in the short term, more modest steps could be taken. For example, universities could formally recognise and allocate workload time for staff who identify as members of particular communities or cultures to contribute to ethical review processes. This would allow lived experience and community knowledge to inform research governance in a more meaningful and systematic way - a sort of “reverse ethics creep”.

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