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Co-opting the “neuro” in neurodiversity and the complexities of epistemic injustice

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ABSTRACT

This article tackles the theoretical thinking behind PPI and inclusion, input from people with neurodiverse conditions. By providing a perspective on how the prefix “Neuro” is positioned in a neutral and authoritative way (exemplified through our brief review of articles within *Cortex*), we explore how “epistemic injustice” (a concept used frequently in law, politics, philosophy and social science) can potentially arise. Epistemic injustice typically refers to a pernicious power dynamic whereby oppressed groups are silenced (Fricker 2007), either because certain voices are not given weight (“testimonial injustice”), or the ways in which they are allowed to speak (e.g., interpret their own experiences) are limited (“hermeneutical injustice”) (Kidd and Carel 2016). We show how, for “neurodiversity”, the mainstream “neuro” narratives are often positively felt by those deemed to be neurodiverse, and the lines between oppressor and oppressed break down, as both neuroscientists and people with neurodiverse conditions co-opt and influence each other’s positions.

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1. Introduction

This *Cortex* Special Issue called for Patient and Public Involvement (PPI). This *Viewpoint* article addresses the theoretical thinking behind PPI’s input from people with neurodivergent conditions. We explore how “epistemic injustice” (a concept used frequently in philosophy, law, politics, and social science) can potentially arise. Epistemic injustice typically refers to a pernicious power dynamic whereby oppressed groups are silenced (Fricker, 2007), either because certain voices are not given weight (“testimonial injustice”), or the ways in which they are allowed to speak (e.g., interpret their own experiences) are limited (“hermeneutical injustice”) (Kidd and Carel, 2016). We show how, for “neurodiversity”, the mainstream “neuro”

narratives are often positively felt by those deemed to be neurodivergent, and the lines between oppressor and oppressed break down, as both neuroscientists and people with neurodivergent conditions co-opt and influence each other’s positions.

2. PPI

‘PPI’ is a familiar term to most UK-based researchers in neuroscience, medicine and psychiatry. It is a mandate that has been adopted by various biomedical research funding agencies, as well as this *Cortex* special issue. The idea is that in the past medicine excluded patients themselves from the research process (Milton, 2014). By doing so, scientists often missed

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crucial experiential information, a loss of a specific kind of knowledge that scientific research does not cover, and potentially information about what matters to patients concerning their own conditions. This is aggravated when science is inaccessible to neurodivergent people. To counter this, PPI mandates that research, specifically neuroscientific and medical research, should include the voices of people with lived experience of neurological and other conditions who have been marginalised and incidental to the research process in the past. Without PPI, we risk loss of trust in health research, healthcare systems, and practices. And all the imbalances above can create conditions liable to sustain injustice.

Over the last twenty years, members of the autism rights and neurodiversity movements have made valid claims to be included in research agendas claiming expertise through lived experience (Milton, 2014). The neurodiversity movement broadly opposes cure, instead operating an affirmative model of disability that i) values autistic and other neurodivergent traits and ii) challenges deficit models (Kapp et al., 2013; Walker, 2021). To aid them, PPI is clearly designed to alter and amend power structures in favour of disadvantaged groups as it especially challenges who has the authority or expertise to speak. Even so, whether PPI has been carried out meaningfully in past studies on neuroscience and neurominorities has been questioned, with some research suggesting scientists think of PPI as a tick box exercise (Buck et al., 2014). Our own work suggests sometimes biomedical and neuroscientists only co-opt patient voices that are already sympathetic to their research agendas, in a process known as selective PPI (Russell et al., 2018).

In order to think through PPI with reference to “neuro” studies more generally, it is useful to refer to medical authority and the philosophical concept of “epistemic injustice”, which allows us to examine the way that “neuro” studies and the neurodiversity movement are positioned in relation to medical authority.

3. Introducing epistemic injustice

Epistemic injustice refers to injustice on matters epistemic, namely, concerning the generation of knowledge and understanding within social practices, relationships, and systems. Intuitive examples involve forms of silencing, distortion, and misrepresentation. The basic insight behind work on epistemic injustice is that, while there are well-recognised forms of practical and material injustice in terms of what is physically done to people, or the extent to which individuals are accommodated within society, there are also epistemic injustices, injustices in terms of what stories, narratives, sources of information are given due authority or credence, and are allowed to spread and have influence. In short, someone can be unfairly harmed, and be the victim of an injustice, without being directly, physically harmed, but rather on an epistemic level: their story is disvalued, ignored, distorted, and so on. A further clarification is that the relevant harms are not only to the individual in question, but can be to others, and to the community as a whole.

The notion of epistemic injustice was introduced by Miranda Fricker in a book of that title (Fricker, 2007). In the original formulation, presented in this book, Fricker

distinguishes two kinds of epistemic injustice: *testimonial injustice* and *hermeneutic injustice*. Testimonial injustice involves the way in which someone's testimony is unjustly received: its credibility may be undermined, or it may be downplayed or ignored in certain ways. For instance, autistic individuals who have transgender identities are sometimes questioned; their gender identities have been dismissed as an aspect of their autistic symptoms, i.e., not understanding social (gendered) rules (see Bouzy et al., 2023 for a review). Hermeneutic injustice involves not so much how the testimony is received, but how it is packaged and interpreted: it involves interpretative distortions, or obstructions to individual and collective efforts at understanding. In hermeneutic injustice people are robbed of the interpretative tools (i.e., words, concepts) to accurately and authoritatively get across relevant information. As Chapman and Carel (2023) have recently argued, prior to the emergence of neurodiversity narratives and conceptualization, autistic individuals (and society at large) were blocked from being able to conceive of autistic flourishing, of the good autistic life, let alone live up to it.

Kidd, Spencer and Carel (2022) have reviewed the complexity added to the existing two components. For example, onto testimonial injustice, there has been the suggested distinction between structural and agential testimonial injustice (Wanderer, 2017). In other words, sometimes people are silenced and ignored because people silence and ignore them. At other times, it is simply the results of the way that our institutions are structured.

One interesting development is the phenomenon of “epistemic appropriation” (Davis, 2018), in which “marginalized knowers are harmed through the dissemination and intercommunal uptake of their epistemic resources, in ways that detach those resources from the knowers who created them. Moreover, such resources are utilized in dominant discourses in ways that disproportionately benefit the powerful” (Kidd et al., 2022, p.3). We add a category of “epistemic co-optation”, where the direction is reversed. Here the conceptual resources of the authoritative (e.g., the “neuro”) get “co-opted” by the marginalized in ways that risk having distorting effects upon the lived experience. We argue that as neurodiversity movement advocates are included in research via PPI, and researchers become neurodiversity advocates, there is a mutual influence on how the brain is read, how the discipline is performed, and on our framing of neurodivergent people.

The focus of work on epistemic injustice has tended to be, not so much on individual instance of epistemic injustice, but on more societal and systemic forms (of which individual cases may prove to be illustrative case-studies). Thus, work on epistemic injustice has focused on racist, misogynistic, and able-ist forms of epistemic injustice, that have pointed to structural forms of silencing and distortion to which ethnic minorities, women and disabled individuals are subjected. More recently, and as already mentioned, there have been applications in medicine, including psychiatry (Kidd et al., 2022) and neurodiversity (Chapman and Carel 2023). For these authors, psychiatric service users and neurodivergent individuals are broadly seen as an oppressed minority, exemplified by their exclusion from the processes of science and medicine.

4. Neurodiversity as epistemic justice?

One might think that PPI and the neurodiversity movement can be straightforwardly seen as a form of epistemic justice: a corrective, as it were, to the epistemic injustice of oppressive neuro-normative outlooks. Indeed, [Chapman and Carel \(2023\)](#) convincingly argue that neurodiversity narratives recast the way in which certain conditions are conceptualised, opening up a space of possibilities that allows wellbeing and good life among neurodivergent individuals. While this seems to us to be a valuable insight, we would like to explore some complications to the idea that neurodiversity narratives straightforwardly combat epistemic injustice.

‘Neuro-’ is usually framed as neutral and authoritative, which may seem innocuous but, of course, it supports an orchestra of background funding mandates, disciplinary norms, research careers and shared beliefs and values. It is this same construction of the body in neurological terms, so called ‘neuro-centrism’ used by both the neurodiversity movement and neuroscience: where brain structure and physiology is seen to account for every human behaviour obscuring that neuroscience is one lens amongst many ([Satel and Lilienfeld, 2013](#)). Likewise, the overuse of the prefix has been dubbed “Neuromania” ([Tallis, 2014](#)), an over adoption that illustrates the epistemic strength and influence of neuroscience, deriving part of strength from being a technical disciplinary practice.

Of course, the neuro-prefix is adopted by the neurodiversity movement. In a very similar way to neuroscience, a neuro-authority is forged. This authority is based around and reliant on the language of neurological differences that the scientists themselves have exploited so effectively to gain traction. The ‘Neurodiversity’ movement paints differences primarily in terms of innate neurology, the brain. To underpin claims for rights, the movement cites neuroscientific research that differentiates autistic brains from a normal brain to provide authority for their claims. In this way neurodiversity activists co-opt the authority of a model derived from neuroscientific research. And people who identify as neurodivergent co-opt the language of science both in order to be taken seriously but also to forge an identity based on neurological difference. This understanding of oneself as being identifiable by one’s neurology is often championed by those deemed to be neurodivergent. Sociologists like [Rose \(2006\)](#) have referred to their ‘neurochemical selves’, and [Ortega \(2009\)s](#), to ‘cerebral subjectivity’.

The first-person experiences give science a legitimacy it cannot gain from objectivity alone. For example, in drafting the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria for autism, the neurodevelopmental scientific expert panel was in conversation with ASAN, the autistic self-advocacy network, based in the US (the specific influence these autistic self-advocates had on the process is described in detail by [Kapp & Ne’eman, 2020](#)). This allowed the panel credibility amongst what may have been fierce activist opposition to DSM changes. ASAN had a unique authority in virtue of their first person narrative, lending scientific experts credibility. Another example is AIDS

activism in the 1980s. Epstein shows how in the US, gay activists countered negative stereotypes by becoming accepted experts in order to co-opt the scientific agenda and become included in drug trials ([Epstein, 1995](#)). Studies elsewhere have shown how patients’ and activists’ groups take charge of funding. Here, changing funding agendas are about co-opting dominant discourse to re-establish and reorder existing power dynamics, often ‘from within’ medicinal specialities to contribute to new epistemic and political appraisal of causes and conditions ([Rabeharisoa et al., 2013](#)). Notably the example above could be considered PPI; a form of meaningful PPI (usually led by the patients).

As neurodiversity has expanded as a concept, many scientists themselves have started to identify as neurodivergent. Neurodiversity activists have learnt the language of science in order to be taken seriously by the medical establishment they lobby. Rather than two polarised groups, there are hybrid groups containing neurodivergent scientists and scientific neurodiversity activists. And finally, the concept of neurodiversity, which is a product of its historical and social context, has been co-opted by science as this issue testifies. In this way, the lines between oppressor and oppressed break down, as both scientists and people with neurodivergent conditions co-opt and influence each other’s positions.

Another complication to the straightforward oppressor/oppressed relationship is representativeness. The representatives of neurodivergent people in PPI are often verbal, have above average IQ ([Russell et al., 2019](#)). This means another form of testimonial injustice potentially occurs. If only one type of neurodivergent voice is heard it potentially erases or minimizing the experiences of neurodivergent folk who are non-verbal and severely disabled ([Hiari, 2018](#)). A risk of co-option is that in attempting to co-opt the dominant resources, minorities are overpowered. Moreover, attempts at co-option potentially lead to reverse engineering, where minority groups adopt the values and attitudes of those whose powers or systems they are trying to regulate/co-opt.

5. Conclusions

To summarise, with the co-option of each other’s messages, the mixing of expertise and the potential for injustice wreaked on non-verbal more impaired populations, the relationship between the neurodiversity and science communities is not as straightforward as one side being the victim, and the other the perpetrator of injustice. This is a situation that is not unique to neurodiversity, of course it occurs throughout clinical biomedical research. Instead we think of the two actors; neuroscientists and the neurodivergent population as symbiotic and intertwined. Each in its own way relies on the other for authority.

The take-home message is not that PPI should not be engaged in, but that it should be done so with great care, if it is to genuinely correct epistemic injustice. Furthermore, we should be especially careful of performative and tokenistic “PPI-washing” where PPI is used as a screen to hide injustices behind.

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