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Special issue "Neurodevelopmental Neurodiversity": Viewpoint Diversity, epistemic injustice and medicalization

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ARTICLE INFO

Article history:

Received 3 October 2023

Reviewed 28 December 2023

Revised 26 January 2024

Accepted 11 March 2024

Action editor Punit Shah

Published online xxx

Keywords:

Neurodiversity

Autism

Psychiatry

Medicalization

ABSTRACT

This Viewpoint explores challenges within the neurodiversity framework, with a particular focus on autism, and discusses three critical aspects: the risk of epistemic injustice, the balance between over and undermedicalization, and the terminological complexities associated with the “neuro-” prefix. It underscores the importance of a balanced approach that avoids overmedicalization while providing essential support, addresses concerns about the indiscriminate use of “neurodiverse”, questions the terminology on neurodiversity, and suggests considering a broader term like “biopsychosocial diversity”. Ultimately, this Viewpoint advocates for a measured approach to neurodiversity, emphasizing historical context and a diverse perspective to foster collaboration between cognitive science and behavior research.

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Australian sociologist Judy Singer, in 1998, introduced the term “neurodiversity” to champion the rights of autistic individuals. The notion of neurodivergence broadly includes any neurocognitive variation associated with belonging to a marginalized or minority group (Walker, 2021), integrating people living with a particular developmental condition (e.g., autism) or any other atypical sensory and communicative experience (e.g., aphantasia) (Sierpowska et al., 2020). In the neurodiversity ecosystem, co-creation between researchers and autistic people supports the development of “epistemically just and empirically valid” practices (Botha, 2021), and the integration of sociological or experiential questions with cognitive approaches is certainly particularly important for

the future of mental health and neuropsychology (Alderson-Day & Pearson, 2023). Nevertheless, neurodiversity has evolved into a multifaceted movement encompassing scientific, social, and activist domains, each interwoven to advance mental health. This expansion beyond scientific boundaries necessitates a comprehensive perspective of the intricacies inherent in the concept of (neuro)diversity.

This Viewpoint aims to offer valuable conceptual insights aimed at navigating some of the potential challenges posed by the neurodiversity framework. Our primary goal is to expand upon the traditional understanding of neurodiversity and enhance our understanding of neurodivergence, particularly using nuanced perspectives and careful consideration, with a

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<https://doi.org/10.1016/j.cortex.2024.03.003>

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focus on autism as an illustrative example. Such perspective is crucial to safeguard against the unwarranted expansion of the epistemic scope of testimonies and symptoms described in a condition like autism. Three crucial concerns regarding neurodiversity will be addressed.

First, on a clinical level, an unqualified embrace of neurodiversity carries the potential danger of constraining access to crucial medical and social interventions. As underscored by many authors, a certain number of symptoms, such as perceptual symptoms or qualitative differences in social and pragmatic communication, could indeed be considered a strength within the context of autism, deserving further medical exploration. However, a significant portion of individuals diagnosed with autism endures challenges and suffering associated with their condition (Lord et al., 2022). Of course, neurodiversity has never denied the difficulties that certain people may encounter due to their specificities. On the contrary, it calls for the implementation of suitable support systems aimed at facilitating the full participation of all individuals in society. However, it is essential to recognize that those who are undergoing significant suffering are often the ones whose experiences receive the least acknowledgment. They tend to face the greatest difficulties in articulating their hardships and having their voices heard. There is a notable risk that the individuals who express themselves less within the discourse of neurodiversity are precisely those most in need of support. When a person's credibility is questioned or when they encounter challenges in clearly conveying their emotions and experiences, there is a real danger that their narratives may be downplayed or disregarded, a phenomenon that can be aptly described as “epistemic injustice” (Nicolle & Gauld, 2022). Could the promotion of neurodiversity inadvertently lead to the perpetuation of epistemic injustices? Once again, without implying any negation of the neurodiversity paradigm or the importance of gaining a deeper understanding of cognitive and emotional diversity, such a question should at least be raised.

Moreover, in the era of self-diagnosis, neurodiversity could potentially become a new and widely adopted “label” for a significant number of people. However, it is crucial to exercise caution and thoughtfulness in this expansion. There is a legitimate concern that an unchecked proliferation of neurodivergent self-identifications. It is essential to recognize that labeling individuals carries both positive and negative implications. While labels can serve as a means of self-recognition and empowerment, they can also inadvertently perpetuate stereotypes and lead to potentially harmful generalizations. The term “neurodiverse” is no exception to this principle. It is important to recognize that some differences require specific care and/or more specific social support than others. Additionally, when individuals identify with a particular category, it can inadvertently perpetuate stereotypes. Terms like “special” and “exceptional” can be regarded as pejorative and as not fully respecting the rights of the people concerned. For instance, automatically associating someone with autism solely with exceptional skills in areas like mathematics or computer science, while characterizing her/him as asocial, is a simplistic and unfair portrayal of the diverse range of abilities and personality traits within the neurodivergent community (Bloch et al., 2023). This example serves as a

compelling reminder of the necessity to wholeheartedly embrace the concept of neurodiversity while also employing it with a vigilant and judicious approach.

Furthermore, aligning with feminist standpoint theories (Harding, 2004), neurodiversity could consider that the qualities and disabilities of each person are all valid depending on the adopted point of view. Notably, in various scientific discussions and publications about neurodiversity, there is limited opportunity to investigate certain unique aspects of autism that might pose potential harm to an individual. Embracing the principles of neurodiversity may consequently prompt a reevaluation of the traditional demarcation between normal and pathological. However, preserving this distinction remains vital to prevent both overmedicalization and undermedicalization. Certainly, neurodiversity serves as an effective counterbalance to the risk of overmedicalization, which refers to the idea that medicine has excessive authority over people who do not need to be treated as ill/sick. Nevertheless, neurodiversity can also lead to a risk of undermedicalization, wherein certain individuals might be denied rightful access to acknowledgment of their health condition, along with the associated rights and benefits that come with it. For example, a person with autism may experience difficulties with social communication in an environment where social norms are highly structured, which can have a negative impact on her/his social or professional life. Even if this person has exceptional abilities in other areas, such as creativity, she/he may suffer in these social situations. Disregarding the suffering experienced by this individual could be profoundly detrimental to her/his overall well-being. Once again, it is important to underscore that neurodiversity does not dismiss or negate the existence of suffering or harmful health conditions. However, here again, it is imperative to strike a delicate balance in applying this concept: we should neither fall into the excess of categorization and pathologization, nor failing to recognize the need for medical or social support when necessary.

Lastly, from a purely terminological perspective, one might ponder whether the incorporation of the prefix “neuro-” in “neurodiversity” implies that the brain is the primary – if not the sole – determinant for comprehending human diversity (Chamak, 2015). Furthermore, with the emergence of many fields associated with the prefix “neuro-” (including neuroeconomics, neuromarketing, neuropolitics or neuroeducation), the term “neurodiversity” could potentially be viewed as nothing more than a buzzword, strategically employed to lend an air of scientific rigor to the broader concept of diversity. Paradoxically, even though neuroscience terminology has been employed to validate and furnish the neurodiversity movement with a suitable lexicon, neuroscience seems to have played only a relatively minor role in shaping the development of the notion of neurodiversity (Forest, 2022). We express our regret that, to the best of our knowledge, no author in the clinical literature has raised critical questions concerning this term. To avoid the excessive connotation of this prefix, an alternative approach to embracing diversity could be considered. This approach would encompass neurological, biological, psychological and social dimensions – each of which is pertinent to comprehending the experiences of individuals who deviate from pre-

established norms in their functioning. Although some authors have proposed to use the term of “psydiversity” (Evans, 2021) – which may unfortunately renew a traditional opposition between the “neuro” and the “psycho”–, we advocate for an expansion of the “neurodiversity” term to these four dimensions. For instance, the use of the term of “biopsychosocial diversity” might seem to better emphasize the diversity in experiences and psychological functioning of individuals.

To conclude, whatever the scientific concept passed through the prism of this paradigm (e.g., social communication or perceptive particularities), we call on the community to be wary of an overenthusiastic approach to neurodiversity – while unconditionally embracing its principles of inclusion, respect and equity for all. We support a measured and cautious neurodiverse stance. To further advance the dialogue between cognitive science research and behavior research, we emphasize the importance of concurrently developing an understanding of the historical evolution of the neurodiverse community, and an intrinsically diverse perspective of the notion of neurodiversity itself.

Funding

No funding was provided.

Informed consent statement

Not applicable.

Data availability statement

Not applicable.

CRedit authorship contribution statement

Christophe Gauld: Conceptualization, Resources, Writing – original draft. **Lucie Jurek:** Conceptualization, Supervision, Validation, Writing – review & editing. **Pierre Fournernet:** Conceptualization, Methodology, Supervision, Validation.

Declaration of competing interest

The authors declare that they have no conflict of interest.

Acknowledgments

Any.

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