Not Your “Typical” Research: Inclusion Ethics in Neurodiversity Scholarship

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COMMENTARY

Not your “typical” research: Inclusion ethics in neurodiversity scholarship

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Research focusing on neurodiversity1 is critical for including all marginalized populations in the organizational diversity literature and for promoting theoretical innovation. It is imperative that such research models the ethics of inclusion (Gowen et al., 2019; Nicolaidis et al., 2019). Despite positive intent, majority group researchers have historically produced biased scholarship on novel marginalized populations (Colella et al., 2017). As all research includes some subjective bias, neurotypical researchers are likely to publish information that further marginalizes neurodivergent people as they inherently do not have the lived experience of being neurodivergent themselves. Researchers should include the perspectives of the members of the populations they are conducting research on and aim to support neurodivergent voices. We recommend that researchers (a) include neurodivergent research team members3 when researching neurodiversity and (b) strengthen the marginalized participant impact on research findings through methods like qualitative and participatory action research, especially if including neurodivergent research team members is not feasible despite legitimate attempts to do so.

The trendiness of neurodivergent populations and troublesome examples

Mainstream interest in neurodiversity in the United States has increased drastically over the last two years (Google, n.d.). The lack of living neurodiversity experience among those who control the media narrative is evident. Autistic characters are often portrayed as having cognitive superpowers, and characters with ADHD are portrayed as being “lazy,” “stupid,” or “deviant.” Dyslexia is also presented from the neurotypical perspective—unrealistically as a gift, limitation, or joke. Without the input and scrutiny from marginalized communities, academic literature is similarly

1Neurodivergence is defined as “having a mind that functions in ways which diverge significantly from the dominant societal standards of ‘normal’” (Walker, 2021). In this paper and for brevity we refer to the identities mentioned in the focal article (LeFevre-Levy et al. 2023) we are responding to: (a) autism, (b) ADHD, and (c) dyslexia. The neurodiversity movement is inclusive of all forms of neurodivergence (Walker, 2021).
2We use neurodivergent instead of neuroatypical because neuroatypical only is one letter different from neurotypical. Neurodivergent is likely to be a more inclusive term, particularly considering the needs of people with dyslexia. Indeed, one of the neurodivergent authors of this paper did not realize that the focal article was about neuroatypicality as opposed to neurotypicality.
3Identities of authors on this publication include the following and are anonymized: autism, CPTSD, neurodivergence, sensory processing disorder, anxiety, and ADHD.

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likely to disseminate partial, inaccurate, or even detrimental information. Publishing research about neurodivergent populations designed and interpreted according to neurotypical assumptions can hinder neurodivergent peoples’ employment. This is particularly important considering the already troublesome unemployment rates of neurodivergent people.

Lessons learned from clinical literature

It is critical to examine the problematic history of studies on neurodivergence in the clinical literature to understand how research guided by neurotypical assumptions can harm neurodivergent populations. Some clinical researchers have characterized autistic people as “emotionless” (Mundy, 2009) and grouped them in the same category as “great apes” (Tomasello et al., 2005). It is common practice in experimental designs to compare neurodivergent individuals to “healthy” or “normal” controls, implying that neurodivergent individuals are unhealthy or deviant (Bora & Pantelis, 2016). Despite disapproval of the terminology “high/low functioning” by neurodivergent communities (see Kenny et al., 2016), this language appears frequently in the autism and ADHD literatures. Although some may assert that rhetoric is inconsequential, such language can impact the way society perceives those groups, contributing to stigmatization (Walker, 2012). Such ableist language likely reflects systemic and unconscious bias, and stems from the times in which many of these studies were published, along with restrictions of the clinical field (i.e., the medical model). Although not intentionally discriminatory, ableist language may contribute to interpersonal tension and mistrust, and thus hinder professionals’ capacity to serve populations that their work intends to benefit. It is critical to acknowledge and learn from prior mistakes to prevent them in the future.

Advantages of including neurodivergent people in research about neurodiversity

Including neurodivergent people in research focused on neurodiversity has many benefits. Many of these benefits are gained from centering research on a target population (i.e., research of neurodivergent people, not about neurodivergent people). First, because neurodivergent people are experts of their own identities, they are naturally the most informed about the topic due to their lived experiences. Specifically, lived experiences lead to novel and creative ideas about a subject and can help broaden the understanding of the thinking and reasoning of neurodivergent people. For example, neurodivergent researchers may provide context for study outcomes that focus on neurodivergent workers, such as environmental sensory influences, that neurotypical researchers may not consider. Second, neurodivergent people are likely to be the most informed about the most respectful ways of addressing their communities. Terminology for marginalized groups is ever evolving due to the rejection and reclamation of discriminatory terms traditionally used by others for oppression (Walker, 2012). Third, the inclusion of neurodivergent people in research about neurodiversity is a way of acknowledging their labor and expertise that often goes unrecognized. Specifically, neurodivergent people have likely produced knowledge about the inclusion of their group in less formal ways (i.e., blogs, online forums, social media, consulting, or reviewing). This work, which may not be typically accessed by neurotypical people, contributes uniquely valuable lived experience perspectives.

Neurodivergent researchers are available for collaboration

To align this commentary with our ethical position, this subsection highlights neurodivergent scholars who publish on neurodiversity. The first two authors reached out to our professional networks in I-O psychology. We received responses from six PhD students and recent graduates with multiple neurodivergent identities who were interested in collaboration from a single listserv.
request. These researchers focus on a variety of subdisciplines, providing potential for many streams of inclusive research. This example highlights that neurodivergent researchers and collaborators can be found with minimal effort. Additionally, the first two authors reached out to two neurodivergent researchers who are known in organizational psychology. Dr. Praslova is an autistic researcher focused on diversity and inclusion. She recently developed the Canary Code model for neurodiversity and intersectional inclusion, which focuses on systemically removing barriers faced by marginalized workers (Praslova, 2022). She also writes accessible pieces on neurodiversity and leadership for the Harvard Business Review and Fast Company. Dr. Kocum is a neurodivergent researcher who focuses on centering research on marginalized populations (Robinson et al., 2015). She currently focuses on developing employment standards for workplace accessibility and designing university courses that allow students to consult with organizations on equity, diversity, inclusion, and accessibility initiatives.

Inclusion strategies for neurodiverse research teams

It is common for neurodivergent people to mask their identity-stereotypical behaviors to increase acceptance, which can result in a toll on the individual’s personal resources and well-being. Hence, it is critical for neurotypical research team members to reduce the need for neurodivergent team members to assimilate. Research team members should critically reflect on how their standpoints influence the research and their collaboration (i.e., reflexivity). Additionally, Praslova’s (2022) recommendations for inclusive workplaces (the Canary Code) can be applied to research collaborations. The Canary Code practices for including the most marginalized include: (a) focus on participation, which refers to including individual employees in the work-design process; (b) focus on outcomes rather than on “professional appearance,” presenteeism, or work style; (c) focus on flexibility as opposed to an arbitrary time, place, and work-style barriers; (d) prioritizing organizational justice, which includes the fairness of outcomes, procedures, interpersonal treatment, and providing sufficient information to employees; (e) practice transparency and clear communication, which reduces ambiguity for those who may not register implicit information; and (f) use valid tools for decision making, which underscores the need for direct assessment of skills essential for job requirements.

Applying each of Praslova’s (2022) recommendations to academic research, collaborators should (a) collectively determine a detailed project completion plan and focus on the completion of tasks rather than the ways in which tasks are completed; (b) remain flexible to the time, place, and work style needs of team members; (c) ensure task completion assignments, methods, and authorship decisions are discussed in advance; (d) take notes and ensure that all members of the research team are included in information sharing; and (e) make compensation decisions (through grant funding, authorship, etc.) transparently and collectively based on performance outcomes rather than implicit interpersonal politics. APA guidelines specify that “anyone involved with initial research design, data collection and analysis, manuscript drafting, or final approval” makes a substantial contribution (APA, n.d.). As such, authorship can be warranted when representatives of marginalized populations review manuscripts for final approval. When authorship is not desired, marginalized individuals should be compensated in other ways out of respect for their expertise, knowledge, and time.

Supplemental methods of neurodivergent community control over research

Although including neurodivergent researchers as full collaborators is ideal, we offer more inclusive research methods when this is not feasible or as a supplement. Qualitative methods can benefit neurodiversity literature by enabling neurodivergent participants to provide open responses that are less restricted compared to pregenerated quantitative scale items, which can reflect
professional researchers’ preconceived notions. Such preconceived quantitative items may not adequately capture the most important phenomena of interest to neurodivergent populations, especially when conceived from a neurotypical perspective. Examining open-ended responses from neurodivergent participants allows researchers to better understand what is most important to the participants, centering the research on their priorities rather than on neurotypical researchers’ objectives.

I-O researchers can draw upon methods rooted in the field of community psychology that promote greater participant involvement in the research process and on the effects of the research. Participatory action research aims to break down hierarchies in professional research by paying “careful attention to power relationships, advocating for power to be deliberately shared between the researcher and the researched” (Baum et al., 2006, p. 854). The perspectives of participants are used to select the research topic, collect data, perform analyses, and determine what action(s) should occur as a result of the findings (Baum et al., 2006). Participants can join professional researchers as part of a research team, influencing the research process as opposed to only being examined (i.e., participant objectification). Participatory action research also includes a behavioral or systemic change component. Organizational action research may result in improving employee working environments, altering discriminatory policies, critically reexamining organizational hierarchies, and highlighting and supporting neurodiversity representation at all levels (Praslova, 2021). For how to ethically include autistic adults in participatory research projects, we recommend reviewing exemplary guidelines provided by Nicolaidis et al. (2019) and Gowen et al. (2019).

References


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