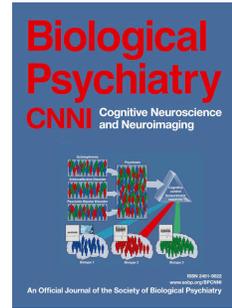


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Expanding DEI to Disability: Opportunities for Biological Psychiatry

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## Expanding DEI to Disability: Opportunities for Biological Psychiatry

[Short Title: Expanding DEI to Disability]

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*Abstract:* Given its subject matter, biological psychiatry is uniquely poised to lead STEM DEI initiatives related to disability. Drawing on literatures in science, philosophy, psychiatry, and disability studies, we outline how that leadership might be undertaken. We first review existing opportunities for the advancement of DEI in biological psychiatry around axes of gender and race. We then explore the expansion of biological psychiatry's DEI efforts to disability, especially along the lines of representation and access, community accountability, first person testimony, and revised theoretical frameworks for pathology. We close with concrete recommendations for scholarship and practice going forward. By tackling head-on the challenge of disability inclusion, biological psychiatry has the opportunity to be a force of transformation in the biological sciences and beyond.

*Keywords:* accessibility; community engagement; disability; disability justice; diversity, equity, and inclusion; pathology

## **Expanding DEI to Disability: Opportunities for Biological Psychiatry**

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Working to make an academic field more diverse, equitable, and inclusive is a physical and conceptual task. It involves rearranging habits, as well as reimagining the core of scholarly and creative activity. Increasingly, STEM (Science, Technology, Engineering, and Mathematics) and related fields, are recognizing the ways in which women, people of color, disabled people,\* and LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Queer+) people (among others) are underrepresented and disadvantaged within their ranks. Studies repeatedly document the challenges underrepresented scholars face in entering STEM fields, starting with the bias about what a scientist looks like and continuing through leaky pipelines, weak mentorship networks, and full-fledged obstacle courses (5). Once in the field, underrepresented scientists continue to face workplace microaggressions and harassment (6-7); inequities in grant funding (8-11), hiring and promotion (12-15), speaking invitations, and teaching evaluations (16-18); and biases in publishing and citations (19-22). These biases and inequities contribute to large scale issues in retention and promotion, and compromise sense of belonging and wellbeing. Ultimately, however, science pays the highest price. Its history and its future are weaker without the contributions of marginalized scientists.

Overwhelmingly, attention to diversity and inclusion in STEM has focused on addressing disparities across gender and race. These efforts, however, have been limited in significant respects. Endeavours to increase gender diversity have worked to improve the representation of women, but left unaddressed other gender minorities (e.g., trans and non-binary people). Similarly, efforts to increase racial and ethnic diversity have typically emphasized Black and Latinx representation, to the exclusion of Asian and Indigenous people. Perhaps even more saliently, few STEM diversification initiatives have addressed disparities in disability.

While biological psychiatry can contribute to diversity on several fronts, the field is uniquely poised to lead STEM integration around disability. Insofar as biological psychiatry deals directly with psychiatric disabilities and disorders—and therefore directly with related disability communities, it is well-positioned to lead in advancing disability inclusion in STEM. In this essay, and drawing on literatures in psychiatry, science, philosophy, and disability studies, we first review existing opportunities for the advancement of diversity, equity, and inclusion (DEI) in biological psychiatry around issues of gender and race. We then explore the expansion of biological psychiatry's DEI efforts to disability, especially along the lines of representation, access, community accountability, first person testimony, and revised theoretical frameworks for pathology. We close with concrete recommendations for research and practice going forward. By tackling the challenge of disability inclusion head-on, biological psychiatry has the opportunity not only to itself be transformed, but also to be a force of transformation in the biological sciences and beyond.

## I. DEI in Biological Psychiatry: A Primer

Efforts to enhance DEI in psychiatry, and biological psychiatry specifically, have emphasized organizational and editorial commitments. These recommendations are critical if the field is to make steady and sustainable advances on these fronts. Important, too, are individual efforts to diversify the field. New emphases on citation ethics (23) and narrative CVs (24), as well as general calls to self-education, offer widely accessible outlets for DEI activity. Moving forward, a blend of recommendations for professional associations, journals and other publications, as well as individual laboratories and scientists, is important.

Scientific bodies such as the Organization of Human Brain Mapping (25) and National Institutes of Health (26) are leading efforts to integrate DEI into the institutional fabric of science. They have proposed a range of inclusive practices that include revising mission and values statements and codes of conduct; enhancing recruitment, retention, and mentorship; diversifying curricula; expanding community outreach; forming DEI committees; rebalancing speaking invitations, conference panels, and Q&A airtime; developing inclusivity training for hiring, promotion, and grant review committees; creating diversity awards; demographic data collection; instituting all-gender restrooms and inclusive signage; improving education and implementation of legally-mandated accommodations as well as best practices for accessibility (25-26). In psychiatry, calls for greater diversity have addressed both the pool of psychiatric practitioners (27) and the structure of psychiatry departments (28). The Society of Biological Psychiatry established an Inclusivity Task Force focused on ameliorating disparities around gender and race (29). And efforts are underway to improve DEI in publishing in biological psychiatry journals (30-32) and in *Biological Psychiatry* specifically (33). These efforts include diversifying journal editors, editorial boards, reviewers, and authors by actively increasing the number of women and/or people of color editing, reviewing, and publishing.

Individuals, too, can play a part in the project of diversifying science, especially scientific publishing. Recent work has identified the marked undercitation of women and people of color in the fields of neuroscience (34-35), communications (36), cognitive science (37), medicine (38), and physics (39) (among others). This overall undercitation holds when controlling for the journal, publication year, author seniority, number of authors, and whether the paper was a review or empirical article. The effect is shown to be largely driven by the reference lists of papers first- and last-authored by men. Importantly, authorial discretion affords authors the opportunity to rebalance their reference lists to reflect existing demographics in the field (or go beyond them). The Citation Diversity Statement (CDS) is one helpful tactic to raise awareness and calculate (and in some cases recalibrate) the balance of one's reference lists. The CDS is a short statement, appended to the paper much like acknowledgments, which offers an account of the citation diversity in that paper's reference list (40-41). The CDS has now appeared in over 30 separate journals, with the biological sciences leading the social sciences in their endorsement (42). Cell Press, which publishes over 50 journals in the biological sciences, now has the option to include a CDS and *Journal of Cognitive Neuroscience* invites a CDS in its submission guidelines (43). Citation diversity is a quickly growing area in STEM DEI initiatives and allows individuals to contribute to the process in meaningful ways.

Overwhelmingly, the STEM DEI efforts listed above have focused on ameliorating disparities along the lines of gender and race or ethnicity. While disability is an acknowledged vector of discrimination in academia, concrete advancements and initiatives have been few and far between. The NIH identifies disabled people as one of the largest sectors lacking in the biomedical research workforce (44). And the Organization of Human Brain Mapping explicitly identifies "accessibility for visible and invisible disabilities" as among the next frontiers of DEI efforts in science (45). *Biological*

*Psychiatry* recently added a statement to its editorial policies indicating it aims to “increase participation among individuals of underrepresented racial, ethnic or gender identities; from underrepresented countries or disadvantaged backgrounds; and those with disabilities” (46). Given the paucity of concrete proposals and practices, however, disability inclusion poses a significant opportunity for initiative and innovation in science.

## **II. Disability in Biological Psychiatry: An Opportunity**

Biological psychiatry, while similar to other STEM fields in many respects, is also unique. Insofar as the field focuses on elucidating the nature and causal mechanisms of psychiatric disability, mood disorders, and other neuroatypicalities, it intersects directly—as a matter of necessity—with disability communities. Biological psychiatry utilizes neuroimaging, psychopharmacology, and neuroimmunochimistry, among other tools, not only to understand psychiatric disabilities and disorders but also, in many cases, to treat them, with a range of cognitive, behavioral, drug, and neuromodulation therapies. As such, where most STEM DEI initiatives merely mention including disabled people, biological psychiatry has the unique opportunity to become a thought-leader in actionable disability inclusion. Here we address four main vectors of that opportunity.

### a. Access and Representation

Across academia, discussions of disability inclusion typically focus on enhancing accessibility in classrooms and conferences. The demands of disability justice, however, are more expansive. Research shows that disabled students with an interest in STEM, faced with systemic barriers in the sciences, often choose not to pursue undergraduate or graduate degrees in STEM fields (47). Those systemic barriers include elements common to underrepresented groups (e.g., lack of mentorship, recruitment, retention, etc.) but also unique to the disability community (e.g., ableist ignorance [48-49] and discrimination, inaccessible buildings and communicative materials, lack of accommodations and adaptive aids) (45, 47, 50). In an April 2021 report, the National Center for Science and Engineering Statistics found that 8.89 percent of PhD awardees in the biological and biomedical sciences reported having one or more disabilities (51). The report also found that disabled scientists and engineers experienced higher unemployment rates and received fewer research assistantships, traineeships, internships, fellowships, scholarships, and grants than those without disabilities. Munoz and Meeks show, furthermore, that grant funding awarded to disabled researchers has significantly declined over the last decade (52). In response to data like these, the NIH formed the Working Group on Diversity’s Subgroup on Individuals with Disabilities to produce a white paper and recommendations, which are projected to include data collection schematics, evidence-based practices and programs, and, most importantly, “perspectives of individuals with disabilities” (53).

Addressing the underrepresentation of disabled scientists and the systemic barriers they face requires a multi-pronged approach (45, 47, 50). Just as some of the barriers (and solutions) are shared across marginalized groups, so too are some of the barriers (and their solutions) unique to disability communities. First, it is critical to develop mentoring networks, hiring and recruitment protocols, and retention practices that focus on supporting disabled scientists and students. We recommend psychiatry departments and biological psychiatry laboratories hire and retain disabled graduate students, postdocs, and faculty, and learn about the unique challenges to creating disability-supportive employment environments (114-116). National psychiatry and biological psychiatry organizations should form committees to monitor the status of disabled scientists, build mentorship pipelines, and highlight disabled scientists’ contributions to the field. They should also implement protocols to counteract discrimination against disabled scientists in grant funding, as well as institute grant funding for disabled scholar-led research. Second, it is critical to improve access and accommodations across

campus: in classrooms, laboratories, and other collaborative spaces. We recommend psychiatry departments and biological psychiatry laboratories, as well as national organizations, enhance universal design in conferences, journals, laboratory protocols, etc. Universal design adapts curricula and learning environments to increase access for the widest range of learners, including those with mobility or sensory impairments, chronic pain, or neuroatypicalities (54, 111-113).

Advances in access and accommodation have historically privileged physical disability; however, psychiatric disability, mental health disorders, and neurodivergence (and their imbrications with physical impairments) are increasingly a focus of disability theory and activism (120). In its efforts toward disability inclusion, biological psychiatry should therefore be informed not only by ADA standards but also disability community recommendations that go beyond them (108). This involves cultivating a robust relationship with disability communities. Indeed, while ableist stigma around physical and psychiatric disabilities compromises the workplace, and disabled scientists should have the right not to disclose their disability in all non-relevant contexts, building a culture of access with and for disabled people goes a long way toward ensuring a creative work environment (117-119).

#### b. Community Accountability

For decades, the disability movement has had the mantra “Nothing About Us, Without Us” (55). While this slogan has primarily been a political call to action, it is also an epistemic intervention. For biological psychiatry, the “nothing” should be understood as the core values that guide the development of treatments for psychiatric disease and disability. Ultimately, these values are a kind of moral knowledge generated by the perception and reasoning of specific individuals with a particular point of view (56-57). Insofar as disabled people are excluded from conversations shaping the basic goals of biological psychiatry, the values generated by their point of view will be excluded from deliberations (58) about the kinds of treatments or therapies the field should use and pursue.

A commitment to this disability moral standpoint can underwrite arguments like that of Sara Goering and Eran Klein, who maintain that “recognition justice” demands engineers, physicians, and scientists “gather and take seriously the input of potential end users throughout the design process” of emerging neurotechnologies, such as brain-computer interface devices (59). More specifically, recognition justice requires “*participatory parity*, such that groups have equal opportunities to enter dialogue regarding matters of justice, and to be heard.” They argue that participatory parity ought to apply to deliberations about the purpose and goals of developing neurotechnologies. As such, the standpoint of disabled people who will be the end users of such technology ought to be valued throughout the design process and not just as a way to market a final product that will be more acceptable to a patient population and maximize sales. In our view, biological psychiatry could lead STEM DEI efforts by adopting this approach and recognizing the viewpoints of disabled people when framing the basic goals of the discipline and doing so as a matter of justice.

Disability inclusion in psychiatric research makes for better science and greater social justice. It allows science not only to calibrate more finely its knowledge and increase impact across diverse populations, but also to redress longstanding patterns of treating disability on a deficit model, as simply a problem to be solved. In the first national study of disabled people’s views on precision medicine research, Sabatello et al. show that while there is widespread willingness to participate, important barriers (especially re: physical access, communication, and information) to disability inclusion need to be removed (60). Beyond involving disabled people in the research, study results should also be returned to the community in accessible ways (61). Non-disabled researchers, need to be trained (and train themselves) in disability cultural competency, and become more aware of

disability experiences, rights, and histories (62-63). In biological psychiatry, some scholars also recommend the inclusion of disabled people among psychiatric researchers and service providers. Participatory approaches to mental health services research emphasize the value of research led by those with lived experience of psychiatric disabilities, as well as the importance of both self-directed care and peer specialists (64-66). In each of these cases, the impetus is to validate individual autonomy, but also to support disability community-led and community-accountable research (67).

### c. Testimony from Disabled People

One concrete form of inclusion is listening to disabled people themselves. First-person testimony from disabled people should not only inform disability inclusion in STEM but it should also inform psychiatric research and practice.

Data rooted in biology, chemistry, neuroscience, among other sciences, are essential for psychiatric researchers and clinicians. It is easy to foreground or otherwise prioritize this data over patient testimony, and disciplines such as psychology or sociology that incorporate it, as the former appear more “objective” than the latter. Yet, this tendency, understandable as it is, is fraught when it comes to appreciating past and present disparities in the equity of care and treatment for disabled people (68-69). Historically, medical practitioners did not simply disregard the first-person accounts and testimonies of disabled people; they actively undermined them, especially in the domains of psychology and psychiatry and often along racialized lines; and this legacy resulted in numerous harms (70-72). Luckily, there is over fifty years of research in the multi-disciplinary and intradisciplinary field of disability studies (73), as well as decades of research in sub-fields such as philosophy of disability (74), that not simply draws upon but centers the lived experiences and testimony of disabled communities. One fruitful nexus between that literature and psychiatry is phenomenological psychopathology, a mixed-methods approach that integrates first-person and third-person analysis and research of psychopathological states (75-79).

Ableist assumptions negatively impact patient-practitioner communication and can lead to increased medical error (82). This is highly relevant in biological psychiatry’s service sector. In a recent survey, 82.4 percent of practicing US physicians report that people with significant disability have worse quality of life than nondisabled people (83). This judgment conflicts with a large body of social scientific research suggesting that people with significant disability—as with non-significant disability—experience levels of quality of life similar to non-disabled people (84-86). Tellingly, just 40.7 percent of physicians expressed confidence in their ability to provide the same quality of care to patients with significant disability as they do to non-disabled patients (83). This is not just a matter of clinical judgment, but also of law. In a subsequent piece, more sobering details from the same study were released: 35.8 percent of physicians “reported knowing little or nothing about their legal responsibilities under the ADA, 71.2 percent answered incorrectly about who determines reasonable accommodations, 20.5 percent did not correctly identify who pays for these accommodations, and 68.4 felt that they were at risk for ADA lawsuits” (87). This raises grave concerns regarding medical education and patient-practitioner communication (88-92).

To take seriously the issue of disability inclusion, qualitative research rooted in the existing lives of disabled people must act as a touchstone. This is true even when such disability literature and activism is ambivalent with respect to biological psychiatry (e.g., the neurodiversity movement) or actively hostile to biological psychiatry (e.g., the C/S/X [consumer/survivor/ex-patient] movement) (80-81). While community accountability and first-person testimony may not be easy to integrate, it is best practice for research and medical practice. While there are longstanding debates concerning how best

to incorporate first-person testimony in ways that positively promote the interests of the patient or patient group in question, there is no lack of suggestions for actionable changes. Lisa I. Iezzoni et al. recommend that disability education be integrated into all levels of medical education; that curricula include an Implicit Association Test disability module; that training facilitate empathy through, for example, house calls; and that trainees learn to pay heightened attention to situations in which disabled patients are especially vulnerable (121-131). Turning to disability *bioethics* in particular, Reynolds and Wieseler recommend cultivating a critical comportment to ‘common sense’ claims about disability and instead embracing critical disability scholarship, which emphasizes testimony by and work from disabled people as well as participatory models of research and practice (132).

#### d. Reframing Pathology

Perhaps the greatest challenge to disability inclusion for biological psychiatry is this: How can a field that deals with physical, neurological, and biochemical pathologies *not* contribute to but rather mitigate the widespread pathologization of disabled people? Today, ableist perceptions and stereotypes are rampant; many people implicitly or explicitly believe that there is something wrong with disabled people, that they need to be fixed, that they are less capable and have less to contribute (93). These biases are precisely what fuel academia’s tendencies not to include disabled people in higher education, provide access measures in classrooms and laboratories, engage disabled people in research, and give the first-person testimony of disabled people the weight it deserves.

While there are numerous ways biological psychiatry (as well as STEM fields in general) can redress the harms of social pathologization, we briefly mention four here.

1. These fields would do well to cultivate a humility about contemporary definitions of “normal function” and health (94). As psychiatrists well know, advances in scientific knowledge and shifts in cultural attunements have, over the centuries, dramatically changed the definitions and treatments of disease (109-110, 133). There is no reason to think changes to current biomedical theory and practice are not imminent and disability inclusion may be one factor in turning the next corner.
2. These fields would do well to resist the logic of cure, which assumes that deviations from “normal function” must be fixed or rectified. Disability theorists repeatedly underscore that to have a disability is not to have a defective body, but to have a minority body (95) or a bodymind (96) representative of the vast diversity in human life forms (97-98). While many disabled people value psychiatric treatment and support services—and rightly advocate for more, there is no reason for *cure* (or the erasure of disability) to be the first or primary response to disability (99).
3. These fields would do well to more consistently and deeply embrace patient choice, whether in the mode of treatment or the selection of treatment at all (100). Patients’ knowledge of their own bodies and their autonomy over their experience of embodiment deserve the utmost respect. Where certain forms of disability, moreover, create the grounds for greater community, patients’ choice to retain those disabilities even in the face of cure deserves validation.
4. These fields would do well to contribute to a greater scientific understanding and celebration of the rich intellectual, emotional, and social capacities that mark disabled bodyminds and disability communities (101-103). Biological psychiatry in particular has the opportunity to underscore and support the creativity and curiosity inherent to neurodiversity (104-107).

While biological psychiatry may need to catch up to some STEM fields in its efforts to expand DEI along the lines of gender and race, the field itself is poised to become a thought-leader in the realm of disability inclusion precisely because it intersects on an everyday basis with disability communities. The four main vectors of that opportunity—access and representation, community accountability, first-person testimony, and reframing pathology—sketch a landscape within which biological psychiatry can begin to play that leadership role. Working with and through disabled scientists and disability communities, moreover, will be critical to that venture.

### III. Practical Recommendations

Based on the literatures in science, psychiatry, philosophy, and disability studies we have reviewed, we offer the following practical recommendations for expanding DEI initiatives in biological psychiatry to disability inclusion.

#### Access and Representation:

- Hire and retain disabled scientists.
- Build mentorship networks for student and junior disabled scientists.
- Enhance accessibility and aids for disabled scientists in classrooms, in laboratories, and on campus.
- Reimagine disability access and universal design at national and international conferences.
- Include disabled scientists among journal editors, editorial boards, reviewers, and authors.
- Include disabled scientists among invited speakers, collaborators, organization leaders, etc.
- Cite disabled scholars, especially when discussing research about psychiatric disabilities.
- Collect data about disabled scientists in local, national, and international psychiatry organizations.
- Institute grants and fellowships for disabled-scholar-led research and disability community engaged research.

#### Community Accountability:

- Include disabled people in study cohorts by default where appropriate.
- Involve disabled people in the development (not simply consumption) of neurotechnologies.
- Train non-disabled researchers in disability cultural awareness.
- Build a pipeline and support for disabled scientists with the lived experience of a psychiatric disability to be among researchers and practitioners addressing that disability.

#### First-Person Testimony:

- Acknowledge first-person testimony of disabled people as a touchstone for disability inclusion, psychiatric research, and psychiatric practice.
- Solicit first-person testimony through participatory research and patient-centered care.
- Train medical practitioners to listen more effectively to their patients.

#### Reframing Pathology:

- Cultivate humility about current psychiatric theory and practice.
- Resist assuming that deviations from “normal function” must, necessarily, be “cured.”
- Honor patient choice and autonomy with respect to psychiatric treatment.
- Celebrate the intellectual and social contributions of disability communities and of people with psychiatric disabilities and diseases in particular.
- Celebrate the scholarly contributions of disabled scientists through, for example, awards, fellowships, citations, and other forms of recognition in science.

#### IV. Future Research and Directions

Of necessity, meaningful disability inclusion in biological psychiatry will change what research looks like, reconfiguring both the lines of its inquiry and the methods by which that inquiry is conducted. First, research questions should continue to explore the understanding of existing diseases, disorders, and disabilities, and the development of affordable and effective treatment for those who want it. In addition, however, investigators should devote greater attention to questions that explore the enhanced capacities certain neurodivergences afford in comparison to control populations. Such research would be centered less in a deficit model and more in a disability gain framework. Second, making research protocols more disability inclusive remains a significant challenge for the field. Common neuroimaging studies employing fMRI typically require participants to lay supine for extended periods of time, which excludes people with chronic pain or claustrophobia. Selection tasks, moreover, that require color recognition, visual acumen, verbal processing, and/or fine motor skills exclude people with blindness, language-processing disorders, and reduction of fine motor function. The problem of co-morbidities or co-disabilities, moreover, complicates things further, often excluding disabled people from a study relevant to one of their disabilities because of another. However, we are hopeful that these challenges to full accessibility can be met in at least some contexts and believe there are good justifications for the field to put forth the effort. Namely, co-disabilities present not just a challenge, but a motivation for including disabled research participants in studies. For example, if certain acquired disabilities arising from traumatic brain injury or spinal cord injury increase the likelihood of co-occurring PTSD, depression, and so on, then *failing* to study these intersections creates a significant gap in knowledge the field cannot simply ignore.

The story both of science and of DEI has yet to be fully written. Where science will go—through what new discoveries, via what methods, and on whose shoulders—has yet to be determined. Similarly, the best practices for cultivating DEI in scholarly endeavors (as in life) may well proceed through an infinite number of revisions and reconfigurations. How we think about psychiatric disorders and diseases—and how we think about disability, for that matter—is sure to change not only in our lifetimes but well beyond them. Committing to enhance disability inclusion in biological psychiatry, then, involves listening to the wisdom available to us here and now, recognizing its limitations but also valuing its contributions. Having drawn on literature in science, psychiatry, philosophy, and disability studies, we outlined a series of vectors along which disability inclusion in biological psychiatry might be pursued. We offer that outline with an open hand. In whatever direction this conversation develops, we hope it involves a richer interface between scientific and disability communities, in which the former, perhaps paradoxically, also learns to follow.

\*Please note that we are deliberately using identity-first rather than person-first language in this essay. For discussion about why we are committed to this approach as part of our DEI efforts, see (1-4).

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