

**Note: This document contains reference to sensitive topics that may be triggering for some individuals. Comments containing sensitive material are indicated within the document.**



## **Public Comments**

**January 18, 2023**

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## Oral Comments

## **Finn Gardiner, M.P.P., Autistic People of Color Fund**

The Autistic Women & Nonbinary Network (AWN) and the Autistic People of Color Fund (the Fund) appreciate the opportunity to submit expanded commentary to the Interagency Autism Coordinating Committee (IACC). AWN is a national nonprofit that supports autistic women, girls, transfeminine and transmasculine nonbinary people, and trans people of all genders. The Fund promotes the advancement, inclusion, and integration of autistic people of color through microgrants and systems change advocacy. Together, AWN and the Fund direct policy research and community advocacy to advance healthy outcomes for disabled people, including high-quality and community-based services and supports, accessible housing and healthcare, integrated employment, and inclusive education.

We encourage the Committee to prioritize funding for research on the disparities and inequities in service provision and outcomes that autistic people of color, queer and transgender autistic people, and autistic immigrants and refugees face. All autistic people are at higher risk of unemployment, poor health, and other adverse outcomes than their nonautistic counterparts, but racism as well as anti-queer, anti-transgender, and anti-immigration discrimination worsen these struggles. When research studies do not include or focus on diverse populations, this lack of information can be misinterpreted as indicating a lower prevalence of autism among these populations. This in turn can lead to underfunding services, programs, and research that could best support and respond to the specific needs of autistic people in marginalized communities.

We urge IACC to prioritize such research topics, including the following:

- **The mental health of autistic people of color, autistic immigrants, and autistic refugees.** Although some studies exist on the prevalence of psychiatric disabilities among autistic people, very few examine the relationship of race, autism, and mental health together. Studies have shown that autistic people, regardless of race, are already more likely to experience anxiety, depression, suicidality, bipolar disorder, obsessive-compulsive patterns, and psychosis.<sup>1</sup> We hypothesize that systemic racism and racialized anti-immigrant discrimination contribute to increased rates and severity of psychological distress among autistic people of color and autistic immigrants and refugees, but we need more empirical research to test this hypothesis and support appropriate funding allocations in the future.
- **The involvement of autistic people in autism research.** For years, autism research has been dominated by the needs, priorities, and experiences of non-autistic people. This means that our voices are often silenced and marginalized. For research to reflect our true needs, priorities, and concerns, it must include us from the start. We encourage IAAC to prioritize research models such as community-based participatory research and community-based participatory action research, as exemplified by research collaboratives like the Patient-Centered Outcomes Research

<sup>1</sup> Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819–829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5); Selten, J.-P., Lundberg, M., Rai, D., & Magnusson, C. (2015). Risks for Nonaffective Psychotic Disorder and Bipolar Disorder in Young People With Autism Spectrum Disorder: A Population-Based Study. *JAMA Psychiatry*, 72(5), 483. <https://doi.org/10.1001/jamapsychiatry.2014.3059>

Institute, the Academic Autistic Spectrum Partnership in Research and Education, and the Human Services Research Institute, all of which are co-led by openly disabled and neurodivergent leaders and support projects with disabled co-principal investigators and research team members.

- **The use of anti-ableist language and approaches.** We support increased funding for high-quality research that is responsive to autistic people’s needs, improves short- and long-term outcomes for autistic people, and reflects the priorities of autistic people who consistently receive the least support, recognition, and access. This includes those who face multiple forms of marginalization, autistic people who are also primary or secondary caregivers for other autistic and disabled people, autistic parents of autistic children, and autistic people with multiple chronic health conditions. To accomplish these objectives, IACC should encourage researchers to use respectful, anti-ableist language and approaches in their methods and published work. Anti-ableist approaches to research enable researchers to address systemic issues that affect autistic people’s health, outcomes, and experiences of our disabilities. Anti-ableist values also invite researchers to consider the ultimate aims and consequential impact of their projects in relation to improving social and material conditions for autistic people.
- **The effects of gender bias against women (both transgender and cisgender women), people with feminine gender expressions and presentations, and any people assigned female at birth with neurodevelopmental disabilities and co-occurring conditions.** For example, endocrine conditions are often connected to the worsening of mood disorder symptoms, with or without psychotic features.<sup>2</sup> Chronic inflammation, a feature common in autoimmune disorders, is more likely to occur in women, people assigned female at birth, and autistic people—and that chronic inflammation can result in autoimmune disorders such as diabetes and cardiac disease.<sup>3</sup> Additionally, all women and gender non-conforming people face significant, well-documented disparities in access to appropriate identification or diagnosis and effective supports.
- **The effects of school disciplinary policies and the school-to-prison pipeline on autistic students of color.** Students with disabilities are disproportionately likely to be expelled or suspended from schools that use zero-tolerance disciplinary policies, as are students of color.<sup>4</sup> Most research focuses on students with disabilities as a

<sup>2</sup> Shoib, S. et al. (2016). Psychiatric aspects in endocrinological disorders: Identifying depressive and anxiety in endocrine patients attending outpatient department - A Study from General Hospital in Kashmir (India). *British Journal of Medical Practitioners*. September 2016, 9(3). <https://www.bjmp.org/content/psychiatric-aspects-endocrinological-disorders-identifying-depressive-and-anxiety-endocrine-patients-attending-outpatient>

<sup>3</sup> McEwen, B. S. (2000). Allostasis and Allostatic Load: Implications for Neuropsychopharmacology. *Neuropsychopharmacology*, 22(2), Article 2. [https://doi.org/10.1016/S0893-133X\(99\)00129-3](https://doi.org/10.1016/S0893-133X(99)00129-3)

<sup>4</sup> National Council on Disability (2015). *Breaking the School-to-Prison Pipeline for Students with Disabilities*. Washington, DC: National Council on Disability. Retrieved from <http://www.ncd.gov/publications/2015/06182015>; Curran, F.C. (2016). Estimating the Effect of State Zero Tolerance Laws on Exclusionary Discipline, Racial Discipline Gaps, and Student Behavior. *Educational Evaluation and Policy Analysis*, 38(4), pp. 647-668. <https://www.jstor.org/stable/44984559>



whole, but autistic students of color may need tailored strategies to protect them from criminalization, suspension, and expulsion. Additionally, autistic students face particularly high rates of restraint and seclusion, which can cause severe injury, death, and lasting trauma.

- **Healthcare experiences of autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees.** These experiences can include interactions with medical professionals and other clinicians, hospitalizations, accessibility in hospitals and clinics, communication barriers, denial of care, lack of parity in insurance coverage, and affordability of healthcare services, among others. Racial disparities negatively affecting Black, Native/Indigenous, Latine, and Asian communities in healthcare service provision and health outcomes are well documented.<sup>5</sup> Additionally, as the Committee may already know, researchers from the University of Cambridge published findings only last year that autistic people were more likely to identify as asexual, bisexual, and “other [LGBTQ+ identities].”<sup>6</sup> Health disparities negatively affecting LGBTQ+ people are also well documented.<sup>7</sup> For that reason, funding research on development and use of guidelines and standards (for example, on cultural competency and communication access) for providing healthcare to autistic people would be beneficial.
- **The rate and effects of homelessness and unstable housing on autistic people.** Some research has shown that autistic people are more likely to be homeless than non-autistic people, but there are relatively few studies.<sup>8</sup> Most of this research has taken place in the United Kingdom, whose sociocultural context is different from that of the United States. Researchers should pay particular attention to the prevalence of

<sup>5</sup> Mateo, C. M., & Williams, D. R. (2021). Racism: a fundamental driver of racial disparities in health-care quality. *Nature Reviews Disease Primers*, 7(1), 20. <https://doi.org/10.1038/s41572-021-00258-1>; Yearby, R. (2018). Racial disparities in health status and access to healthcare: the continuation of inequality in the United States due to structural racism: Continuing racial health disparities. *American Journal of Economics and Sociology*, 77(3–4), 1113–1152. <https://doi.org/10.1111/ajes.12230>; Moy, E., Greenberg, L. G., & Borsky, A. E. (2008). Community variation: Disparities in health care quality between Asian and white Medicare beneficiaries. *Health Affairs*, 27(2), 538–549. <https://doi.org/10.1377/hlthaff.27.2.538>; Cromer, K. J., Wofford, L., & Wyant, D. K. (2019). Barriers to healthcare access facing American Indian and Alaska Natives in rural America. *Journal of Community Health Nursing*, 36(4), 165–187. <https://doi.org/10.1080/07370016.2019.1665320>; Buchmueller, T. C., & Levy, H. G. (2020). The ACA’s impact on racial and ethnic disparities in health insurance coverage and access to care: An examination of how the insurance coverage expansions of the Affordable Care Act have affected disparities related to race and ethnicity. *Health Affairs*, 39(3), 395–402. <https://doi.org/10.1377/hlthaff.2019.01394>

<sup>6</sup> Weir, E., Allison, C., & Baron-Cohen, S. (2021). The sexual health, orientation, and activity of autistic adolescents and adults. *Autism Research*, 14(11), 2342–2354. <https://doi.org/10.1002/aur.2604>

<sup>7</sup> Cicero, E. C., Reisner, S. L., Merwin, E. I., Humphreys, J. C., & Silva, S. G. (2020). The health status of transgender and gender nonbinary adults in the United States. *PLOS ONE*, 15(2), e0228765. <https://doi.org/10.1371/journal.pone.0228765>

<sup>8</sup> Churchard, A., Ryder, M., Greenhill, A., & Mandy, W. (2019). The prevalence of autistic traits in a homeless population. *Autism*, 23(3), 665–676. <https://doi.org/10.1177/1362361318768484>; Kargas, N., Harley, K. M., Roberts, A., & Sharman, S. (2019). Prevalence of clinical autistic traits within a homeless population: Barriers to accessing homeless services. *Journal of Social Distress and the Homeless*, 28(2), 90–95. <https://doi.org/10.1080/10530789.2019.1607139>;