

The Autistic People of Color Fund

2022 Community Priorities Policy Report

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Introduction

Established in June 2018 as the Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment, the Autistic People of Color Fund¹ is a community-led organization committed to mutual aid, redistributive justice, solidarity economics, and community building.

The Fund was created by autistic people of color for autistic people of color, with our core team members past and present coming from Indigenous, Mestize, Latine, Black, South Asian, and East Asian communities. At our core, we are a disability justice organization committed to providing direct support for autistic people of color by redistributing financial resources and mutual aid as a form of community-funded reparations. We provide microgrants to autistic people of color all over the world. Aligning with our values of centering the most marginalized, our grant review process prioritizes queer and trans people, immigrants and refugees, undocumented people, and survivors of interpersonal and state violence. Autistic people of color who receive our microgrants use the funds for surviving, living, and thriving. These microgrants have helped hundreds of autistic people of color pay rent and utilities expenses, obtain adaptive and assistive technology, escape abusive living situations, complete art projects, go to therapy, buy job interviewing outfits, pay outstanding court fines, and more.

The Fund began solely as a project intended to financially support our community, but our growth over the past several years has opened many opportunities, including to expand our work to advance systemic and societal change beyond individual microgrants. We recognize that the way to liberation consists of many paths and strategies across social movements. Now that the Fund has more infrastructure and staff than we did four years ago, we have chosen to pursue policy advocacy as our second path. Our expansion into policy advocacy is deeply motivated by our desire to create long-term, sustainable change, even as we continue to fill the gaps that autistic people of color continue to fall through because of government, corporate, and community neglect, deprivation, and extraction. This work remains rooted in our commitments to disability justice and non-reformist reform. In that vein, we believe in using policy advocacy as a vehicle to support and amplify radical demands for life, love, and liberation from our communities.

In October 2021, we released a survey to directly ask autistic people of color what issues affect them and what existing policies are on their radar. Guided by the survey's results, we write this

¹ The Fund for Community Reparations for Autistic People of Color's Interdependence, Survival, and Empowerment is commonly referred to as The Autistic People of Color Fund or The APOC Fund.

report to name pressing issues and offer a starting point for strategies to address them. We hope this report will help inform and guide those who influence legislative, regulatory, and judicial changes in the U.S. and beyond. Disabled people of color have been silenced, dismissed, and erased in this country—and within the white-dominated disability rights movement—for far too long. It is time for more of our voices to be heard—and we demand action.

Therefore, our 2022 policy initiatives are focused on five strategic areas:

1. Pursuing true health equity through eradicating medical ableism and discrimination
2. Ensuring access to affordable, nutritious, culturally relevant food, and eliminating food insecurity
3. Ensuring economic security and access to meaningful, integrated employment
4. Securing the right to dignified, accessible, and affordable housing fully integrated into the community, and
5. Obtaining equitable and fully integrated educational opportunities

About the Survey

We shared the survey through social media and invited community members to respond. We received 39 responses from autistic people of color in four countries.

BREAKDOWN OF RACIAL/ETHNIC IDENTIFICATION:

Black (Including Descendants of Enslaved and Forcibly Relocated Africans): 20.29%

Brown: 8.7%

East Asian: 11.59%

South Asian: 4.35%

Southeast Asian: 4.35%

Southwest Asian or Middle Eastern: 4.35%

Indigenous American, Native, First Nations or Alaskan Native: 13.04%

Indigenous Hawaiian, Polynesian or Pacific Islander: 1.45%

Latine or Latinx: 11.59%

Mixed-Race or Multiracial: 20.29%

OTHER FACTS ABOUT THE RESPONDENTS

Countries Represented: Brazil, Canada, Mexico and the United States of America

Youngest person: 20

Oldest person: 57

Percentage identified as transgender: 56.4%

Priority #1: Pursuing true health equity through eradicating ableism

Given the widespread medical ableism particularly impacting autistic and other disabled people—compounded by issues of medical racism that people of color experience—the Fund seeks to create opportunities, expand access, and work to achieve health equity for autistic people of color. “Health equity” as defined by the Centers for Disease Control means that every person has the opportunity to “attain [their] full health potential” and no one is “disadvantaged from achieving this potential because of social position or other socially determined circumstances.”²

Ableism is defined as practices or policies that treat people with disabilities as if they were invisible, disposable, and less than human, while taking for granted able-bodiedness as humanity’s default state, according to Dr. Shane Neilson, a Canadian physician.³ Alternatively, the abolitionist community lawyer, educator, and organizer Talila A. Lewis defined ableism in January 2022 as the following:

A system of assigning value to people’s bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people’s value based on their culture, age, language, appearance, religion, birth or living place, “health/wellness,” and/or their ability

² Centers for Disease Control and Prevention. 2019. “Health Equity.” Centers for Disease Control and Prevention. 2019. <https://www.cdc.gov/chronicdisease/healthequity/index.htm>.

³ Neilson, Shane. 2020. “Ableism in the Medical Profession.” *CMAJ: Canadian Medical Association Journal* 192 (15): E411–12. <https://doi.org/10.1503/cmaj.191597>.

to satisfactorily re/produce, “excel” and “behave.” You do not have to be disabled to experience ableism.⁴

The Fund aims to advance health equity for autistic people of color through the following policy advocacy efforts:

Accessibility

- Ensuring that all disabled people access life-saving and sustaining in-person and telehealth medical treatment during public health crises and always
- Advocating for more culturally responsive, accountable, and trauma-informed medical professionals and culturally responsive and accessible health information
- Advocating for deinstitutionalizing as many disabled people as possible during pandemics and always while ensuring all short- and long-term healthcare, housing, and transportation needs are met
- Lowering prescription costs and expanding insurance coverage for specialty medications, including biologics used to treat autoimmune diseases
- Preventing overmedication or inappropriate medication on the basis of stereotypes about disability, especially psychosocial and developmental disabilities
- Incentivizing pharmacies to offer a wide range of compounding services and advocating for insurance coverage for compounded medications
- Decreasing barriers to medications including methadone used to support recovery from unwanted addiction, stimulants used for ADD or ADHD, and opioids used for pain management, that prevent disabled people from having reliable access to necessary medications
- Ensuring that autistic people of color have access to affordable, quality, trauma-informed, and accessible dental care, reproductive healthcare, and all other medical care
- Advocating for more expansive support services for autistic people of color and all disabled people who are victims and survivors of abuse, neglect, and violence

⁴ Talila A. Lewis, “Working Definition of Ableism - January 2022 Update,” TALILA A. LEWIS, January 1, 2022, <https://www.talilalewis.com/blog>.

Accountability

- Advocating for the increased maximum penalty amount for violations of the Americans with Disability Act, up from the current penalty amount of \$75,000 for a single ADA violation and \$150,000 for additional ADA violations
- Pushing for heightened sanitary and distancing requirements for workers in any healthcare setting, educational setting, or other congregate or institutional setting that continues to exist during public health crises
- Advocating for medical, nursing, and allied health profession students to receive meaningful required training, developed by autistic people of color and other disabled people of color, on specific experiences, concerns, and community priorities
- Increasing the number of public health authority inspection visits at institutions with vulnerable, immunocompromised populations to ensure compliance with protocol standards during pandemics
- Ensuring that autistic people of color are aware of and connected to their local Protection & Advocacy Systems agencies, legal aid offices, centers for independent living, and recovery learning centers, in the event they need legal assistance, advocacy, peer support, or technical assistance
- Ending public funding and terminating relevant licensures and certifications for known discriminatory, predatory, or dangerous programs, providers, and treatment modalities, such as applied behavior analysis (ABA) electric shock aversive conditioning treatment

Radical inclusion

- Recruiting and retaining more disabled people of color in healthcare and service provision at all levels from junior to senior leadership so that they meaningfully reflect local, disabled populations and communities of color
- Advocate for LGBTQ+ affirming healthcare and services since autistic people are more likely than our neurotypical counterparts to identify as queer, trans, or LGBTQ+
- Advocate for continued access to remote and virtual care via telehealth options
- Advocate for the decriminalization of drug use and for the adoption of harm reduction policies (e.g., safe injection sites)
- Advocate for access to accessible transportation to healthcare providers and services
- Advocate for a single-payer, universal healthcare system

Transparency

Advocate for more studies on autistic people of color’s experience within the healthcare system (e.g., how the COVID-19 pandemic has impacted autistic people of color)

Priority #2: Ensuring access to affordable, nutritious, and culturally relevant food

According to the United Nations, an estimated 42 million people, including 13 million children, experienced food insecurity in 2021 within the United States.⁵ Households with autistic children are 1.5 times more likely than households with people of other disabilities to be food insecure. Food insecurity among households with autistic people or other disabled people is also linked to the higher costs for healthcare and services these households incur.⁶

Autistic Native and First Nations people living on reservation lands face worsened food insecurity because of the ongoing impact of colonization in destroying traditional foodways. And autistic people who are incarcerated or institutionalized are even further deprived of any meaningful choice and dignity in accessing nutritious, healthy, and accessible food.⁷

Moreover, environmental factors impact dietary behaviors and food related health. As JungJa Park Cardoso mentions in *Negotiating and Navigating Invisible Food Deserts: An Exploratory Study on Foodways of Adults on the Autism Spectrum*, even when autistic people have access to grocery stores, farmers’ markets, and convenience stores that serve healthy and affordable foods, available shopping methods might impact their consumption habits. Some grocery

⁵ Hake, Monica, Adam Dewey, Emily Engelhard, Mark Strayer, Sena Dawes, Tom Summerfelt, and Craig Gundersen. 2021. “The Impact of the Coronavirus on Food Insecurity in 2020 & 2021.” *Feeding America*. https://www.feedingamerica.org/sites/default/files/2021-03/National%20Projections%20Brief_3.9.2021_0.pdf.

⁶ Karpur, Arun, Vijay Vasudevan, Angela Lello, Thomas W Frazier, and Andy Shih. 2021. “Food Insecurity in the Households of Children with Autism Spectrum Disorders and Intellectual Disabilities in the United States: Analysis of the National Survey of Children’s Health Data 2016–2018.” *Autism* 25 (8): 2400–2411. <https://doi.org/10.1177/13623613211019159>.

⁷ Jennifer Sowerwine et al., “Reframing Food Security by and for Native American Communities: A Case Study among Tribes in the Klamath River Basin of Oregon and California - Food Security,” SpringerLink (Springer Netherlands, May 24, 2019), <https://link.springer.com/article/10.1007/s12571-019-00925-y>; Cynthia A. Golembeski, Ans Irfan, and Kimberly R. Dong, “Food Insecurity and Collateral Consequences of Punishment Amidst the COVID-19 Pandemic,” Wiley Public Health Emergency Collection (World Med Health Policy, December 1, 2020), <https://onlinelibrary.wiley.com/doi/10.1002/wmh3.378>.

stores, for instance, are overwhelmingly stimulating (e.g., stores having too much sound, too many other shoppers to interact with, and vendors soliciting unwanted foods).⁸ Food justice includes access to healthy, nutritious, and culturally relevant foods, and also includes access to stores that are built to be accessible to autistic and other disabled people. Food justice is inherently a disability justice issue and plays a pivotal role in addressing the food insecurity crisis that many autistic POC experience.

The Fund aims to increase food security, nutrition, and access for autistic people of color over the coming year by supporting the following policy efforts:

- Expanded food assistance benefits and access (including enrollment and eligibility) for the Supplemental Nutrition Assistance (SNAP) and the Women Infant and Children (WIC) programs
- Increased access to a diverse and nutritious range of food options made available to consumers
- Increasing the minimum wage at the local, state, and federal levels so that food consumers are able to afford food for themselves and their families
- Promoting and expanding Farm-to-School programs so that schools are not burdened by supply chain issues and students have greater access to nutritious, locally sourced food
- Expanding food assistance provisions within emergency relief packages and programs so that individuals affected by the COVID-19 pandemic and other emergencies (e.g., natural disasters) do not have to worry about accessing food
- Expanded hours of access in which autistic people can shop, before or after other customers, so as to reduce the amount of environmental stimuli they experience while shopping

⁸ JungJa Park Cardoso, “Negotiating and Navigating Invisible Food Deserts: An Exploratory Study on Foodways of Adults on the Autism Spectrum,” CUNY Academic Works (dissertation, 2016), https://academicworks.cuny.edu/cgi/viewcontent.cgi?article=2631&context=gc_etds.

Priority #3: Ensuring that autistic people of color have job security and access to meaningful employment

In the United States, disabled people are more likely to be unemployed or underemployed than abled people.⁹ Moreover, on average, autistic adults experience even higher rates of unemployment than other disabled people.¹⁰ The inability to obtain meaningful employment often results in mental health breakdowns and other co-occurring disabilities and chronic illnesses among autistic people. Chronic unemployment can also have devastating consequences in a capitalist society, because employment security is directly tied to housing, food security, and often access to healthcare.¹¹

The Fund will push for policy changes in the following areas as a means of increasing job and networking access for autistic people of color (POC):

- Ending subminimum wages for disabled people, tipped workers, and incarcerated workers
- Advocating for workforce development programs that meaningfully integrate autistic POC
- Advocating for policies that incentivize the recruitment and retention of autistic POC, including: (1) paid leave measures; (2) tax measures that benefit autistic POC; (3) the inclusion of the Disability Employment Incentive Act (S. 630/H.R. 3765) to any Congressional tax legislation package; and (4) the inclusion of disabled people in local, state, and federal contracts or other government-assisted contracts

⁹ “PERSONS with a DISABILITY: LABOR FORCE CHARACTERISTICS — 2020.” 2021. Bureau of Labor Statistics. <https://www.bls.gov/news.release/pdf/disabl.pdf>.

¹⁰ Hedley D., Uljarević M., Hedley D.F.E. (2017) Employment and Living with Autism: Personal, Social and Economic Impact. In: Halder S., Assaf L. (eds) Inclusion, Disability and Culture. Inclusive Learning and Educational Equity, vol 3. Springer, Cham. https://doi.org/10.1007/978-3-319-55224-8_19.

¹¹ Hedley D., Uljarević M., Hedley D.F.E. (2017) Employment and Living with Autism: Personal, Social and Economic Impact. In: Halder S., Assaf L. (eds) Inclusion, Disability and Culture. Inclusive Learning and Educational Equity, vol 3. Springer, Cham. https://doi.org/10.1007/978-3-319-55224-8_19.

Priority #4: Securing the right to dignified, affordable and accessible housing for autistic people of color

An estimated 30 percent to 40 percent of unhoused people in the United States are disabled, including autistic people.¹² HUD regulations also define chronic homelessness as a disability.¹³

In the United States, several federal agencies exist that can support autistic people in securing housing. These include the Department of Health and Human Services (HHS) Center for Medicare and Medicaid Services, which oversees federal grants to states for long-term housing support services; the Department of Housing and Urban Development (HUD), which offers rental subsidies, home purchasing support, and affordable housing development incentives; and the Social Security Administration (SSA), which provides individual income to disabled people to support living expenses, including housing. These programs, however, are often managed at the state and local levels, which means that eligibility and the type of assistance one ultimately receives (if any) will vary depending on one's geographic location. Such a system creates confusion due to its fragmentation.

Additionally, many disabled people face long waiting lists for housing subsidies, vouchers, and public housing programs. Disabled people often experience housing discrimination, both in rental applications or homeownership, and in inability to secure accessible housing. As a result, autistic people of color and other disabled people face limited access to adequate housing and

¹² Paode, Pooja. 2020. "Housing for Adults with Autism And/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs." ResearchGate. Daniel Jordan Fiddle Foundation Center for Public Policy. https://www.researchgate.net/profile/Pooja-Paode/publication/346041472_Housing_for_Adults_with_Autism_andor_Intellectual_and_Developmental_Disabilities_Shortcomings_of_Federal_Programs/links/5fb8202c92851c933f47f1eb/Housing-for-Adults-with-Autism-and-or-Intellectual-and-Developmental-Disabilities-Shortcomings-of-Federal-Programs.pdf.

¹³ <https://www.hudexchange.info/homelessness-assistance/coc-esg-virtual-binders/coc-esg-homeless-eligibility/definition-of-chronic-homelessness/>

shelter.¹⁴ Existing housing stock sometimes isn't conducive to a healthy and happy living environment for autistic people who require more durable or easy-to-clean designs.¹⁵

The APOC Fund aims to expand housing options for autistic people of color (POC) through:

- Advocating for a right to dignified, accessible, and affordable housing for all, including rental- and mortgage-controlled properties that are ensured for autistic POC
- Advocating for a robust (i.e., well-funded) set of policies and programs at the local, state, and federal levels assisting renters and homeowners with utilities and housing repair costs so that their shelters are comfortable and habitable, or relocation in the event (e.g., due to natural disasters) one's shelter is no longer deemed habitable.

Priority #5: Eliminating obstacles in the education system that prevent autistic people of color from having equal access to educational opportunities

Autistic and other disabled people have long fought for radically inclusive, equal access to education in relation to our neurotypical peers, especially since education is a critical path toward reducing poverty and employment barriers. Unfortunately, however, many disabled students continue to face barriers toward equal access to education and autistic people of color (POC) face heightened obstacles.

[Infographic about racial disparities]

For instance, disabled Black students make up only 19 percent of the students the Individuals with Disabilities Education Act serves, they account for 36 percent of the students restrained by school administrators using movement-limiting equipment.¹⁶ Moreover, 85 percent of

¹⁴ Paode, Pooja. 2020. "Housing for Adults with Autism And/or Intellectual and Developmental Disabilities: Shortcomings of Federal Programs." ResearchGate. Daniel Jordan Fiddle Foundation Center for Public Policy. https://www.researchgate.net/profile/Pooja-Paode/publication/346041472_Housing_for_Adults_with_Autism_andor_Intellectual_and_Developmental_Disabilities_Shortcomings_of_Federal_Programs/links/5fb8202c92851c933f47f1eb/Housing-for-Adults-with-Autism-and-or-Intellectual-and-Developmental-Disabilities-Shortcomings-of-Federal-Programs.pdf.

¹⁵ "MA Autism Housing Think Tank," MA Autism Housing Think Tank, September 10, 2016, <http://mahousingthinktank.org/wp-content/uploads/2017/04/WhitePaperFINAL.pdf>.

¹⁶ "Significant Disproportionality in Special Education: Current Trends and Actions for Impact" (National Center for Learning Disabilities, 2020), https://www.ncl.org/wp-content/uploads/2020/10/2020-NCLD-Disproportionality_Trends-and-Actions-for-Impact_FINAL-1.pdf

incarcerated youth have emotional and/or learning disabilities, but only 37 percent were placed in special education in school. Had those young people been properly diagnosed and served while in school, perhaps, their paths would not have led them to incarceration. A separate 2018 National Council on Disability report notes that Black, autistic students are disproportionately placed in more restrictive educational environments.¹⁷

The APOC Fund aims to protect and expand autistic POC's access to a quality and affordable education through:

- Advocating for a ban on isolation (seclusion) and restraining measures that cause mental and physical harm to autistic POC and other disabled POC, and the full integration of autistic POC into classrooms with their non-autistic peers
- Advocating for accountability practices that are rooted in restorative justice, and limitations on the use of suspensions and expulsions (which are disciplinary tools that have a disproportionately, negative impact on Black, Brown, and disabled students)
- Advocating for a ban on law enforcement officers in schools and for the use of more culturally competent and sensitive counselors, social workers and other professionals who are trained in behavioral interventions and trauma-informed support services. The APOC Fund supports a holistic approach that does not further support the school-to-prison pipeline.

Additional Priorities and Issues of Concern in Our Communities

Please know that the aforementioned policy priorities are not the end-all and be-all of the APOC Fund's policy advocacy efforts. There are a number of other policy concerns that our members expressed interest in and that we as an organization hope to address over the next year. The following issue areas are important matters that are of great interest to us, but are not highlighted in the 2022 policy priorities:

- Advocating for holistic communication and wellness practices that empower autistic people and advocating for the eradication of Applied Behavior Analysis (ABA) therapy which, rather than providing affirming support services, encourages autistic people to mask their behaviors and conform to neurotypical expectations.

¹⁷ "The Segregation of Students with Disabilities." 2018. National Council on Disability. National Council on Disability. https://ncd.gov/sites/default/files/NCD_Segregation-SWD_508.pdf.

- Advocating for access to Augmentative and Alternative Communication (AAC), including for young people who are progressing through their childhood developmental stages, and advocating for the Interagency Autism Coordinating Committee to coordinate with more autistic people who use AAC.
- Advocating for a transparent, accessible resource system that directs autistic people of color to information on where to receive government-funded support services or diagnostic and assessment services, for as long as diagnosis and assessment are necessary for access to accommodations, supports, and services
- Advocating for an end to policing and prisons, including psychiatric incarceration, and supporting community organizers and leaders in building and growing sustainable systems of support, care, accountability, and healing grounded in the principles of transformative justice
- Creating solidarity with organizations and people who work on intersectional issues (e.g., groups that provide crisis services and support to LGBTQ+ people, of which many autistic people identify)
- Creating solidarity with autistic people of color led organizations and people outside of the United States

About the Team

Tony Alexander

Tony currently serves as the Director of Policy and Advocacy for the Fund. A graduate of Northeastern University School of Law, he has spent the last several years working with nonprofit and community-based organizations, assisting with their advocacy, community engagement, and policy analysis needs. He believes using collective organizing and policy advocacy, through an intersectional lens, as necessary drivers for bringing about a radical imagination and transformation of liberation. Tony is excited to help the Fund in its mission-driven efforts to empower other multiply-marginalized individuals.

Oluwatobi Maeyen Odugunwa

Oluwatobi currently serves as Program Coordinator for the Fund. They originally joined the Fund as Movement Power Intern through the 2021 Power Up Internship Program (a project of SolidarityIs and the Building Movement Project). Oluwatobi is a recent college graduate who also works as an anti-bias reviewer and editor at a publishing company. As a multiply marginalized person, they have been involved in social justice work since a young age.

Oluwatobi was most recently a student advocate and organizer for LGBTQ rights, and as an autistic wheelchair user, they are now looking to get involved in local disability justice work. They spend most of their days playing with their cat, listening to indie rock, knitting, playing video games, or reading (sometimes all at the same time). Oluwatobi's favorite stims are rocking, flapping, and echolalia.

Lydia X. Z. Brown

Lydia X. Z. Brown is the founder and volunteer executive director of the Fund. They are an advocate, organizer, educator, writer, and attorney whose work focuses on interpersonal and state violence targeting disabled people at the margins of the margins, especially at the intersections of race, gender, class, and sexuality.

Finn Gardiner

Finn Gardiner is a community organizer, advocate, writer, and designer whose work focuses on education, racial equity, accessible technology, community living, and more. He designed this report.

With additional thanks to Shreya Iyer, who joined the Fund as a policy intern through the Fall 2021 experiential learning semester program of The CALL (Capitol Applied Learning Labs), a program of Georgetown University.

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