

Autism, Race, and Mental Health Finn Gardiner, Lydia X. Z. Brown, Natalia Rivera Morales

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Content note: This brief discusses experiences of discrimination, abuse, forced treatment, and suicidality. Please take care when reading and know that you can take breaks as needed.

Note: First, we're based in the United States and are most familiar with U.S. laws and policy, so our data, resources, and recommendations reflect that context. As we expand our reach, we plan to include more information in future briefs about international laws and policies, particularly in countries outside Europe and North America. About the Community Priorities Policy Brief Series

In our 2022 Community Priorities Policy Survey, our survey respondents identified education, employment, food justice, housing, and health as their top policy priorities. In this series of briefs, the Autistic People of Color Fund identifies current shortcomings and suggests policy measures to better enable autistic people of color to thrive as fully integrated members of our communities.



Autistic People *of* Color Fund

Facts about Race, Autism, and Mental Health

Autistic people of color carry the burdens of oppression, marginalization, and generational trauma; we bear the wounds of those who came before us. We face existential threats unfathomable to our white and nondisabled counterparts. Our narratives are flattened, disconnected, and distorted by clinical approaches that fail to acknowledge our wholeness, our complexity, our very humanity. Oppression, trauma, and impersonal care all harm our mental well-being and isolate us from our communities. Although Western psychiatry—whether practiced in the West or exported to the Global South—focuses on "chemical imbalances," an individualized concept of illness, psychiatric incarceration, and medication, mental health is more than that: it is influenced by social and cultural factors inextricable from people's lives.¹

Many statistics show that autistic people and people of color experience higher rates of adverse mental health outcomes, often stemming from the cumulative effects of marginalization and discrimination. These adverse outcomes include increased risks for suicidality, higher rates of depression and anxiety, misdiagnosis of and lack of diagnosis for mental health disabilities, and disparities in treatment access.² These disparities reflect the cultural and socioeconomic inequities that we face.

AUTISM AND MENTAL HEALTH

Autistic people are more likely to experience mental health distress than nonautistic people, including depression and anxiety. For example, in a Finnish study of autistic children's mental health,

¹ Nicola, V. (2019). A person is a person through other persons: A social psychiatry manifesto for the 21st century. *World Social Psychiatry*, Sep.–Dec. 2019, 1(1).. DOI: 10.4103/WSP.WSP_11_19

² Mattila, M.-L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., Linna, S.-L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. L., & Moilanen, I. (2010). Comorbid Psychiatric Disorders Associated with Asperger Syndrome/High-functioning Autism: A Community- and Clinic-based Study. *Journal of Autism and Developmental Disorders*, 40(9), 1080–1093. <u>https://doi.org/10.1007/s10803-010-0958-2</u>; Hudson, C. C., Hall, L., & Harkness, K. L. (2019). Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: A Meta-Analysis. *Journal of Abnormal Child Psychology*, 47(1), 165–175. <u>https://doi.org/10.1007/s10802-018-0402-1</u>; Akinhanmi, M. O., Biernacka, J. M., Strakowski, S. M., McElroy, S. L., Balls Berry, J. E., Merikangas, K. R., Assari, S., McInnis, M. G., Schulze, T. G., LeBoyer, M., Tamminga, C., Patten, C., & Frye, M. A. (2018). Racial disparities in bipolar disorder treatment and research: A call to action. *Bipolar Disorders*, 20(6), 506–514. <u>https://doi.org/10.1111/bdi.12638</u>

nearly half of the autistic children profiled were diagnosed with an anxiety disorder.³ Autistic people of all ages are also about four times as likely to have depression than nonautistic people.⁴

Anxiety and depression are not the only psychosocial disabilities that are more common among autistic people. Autistic people are also more likely than the general population to be diagnosed with bipolar disorder, disordered eating, obsessive-compulsive disorder, obsessive-compulsive personality disorder, schizophrenia, and other nonaffective psychotic disorders.⁵ (Affective disorders include bipolar disorder and major depression. Psychosis can be part of a mood disorder, but it can also exist on its own.) Moreover, autistic people are more likely to show signs of posttraumatic stress response, whether or not they were formally diagnosed with posttraumatic stress disorder.⁶ Repeated exposure to unwanted sensory aversions, Applied Behavior Analysis (ABA) and other compliance-oriented treatment, and stressful social interactions can contribute to or exacerbate posttraumatic stress responses.⁷

⁵ 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. <u>https://doi.org/10.1016/S2215-0366(19)30289-5</u>; 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. <u>https://doi.org/10.1001/</u>jamapsychiatry.2014.3059; Meier, S. M., Petersen, L., Schendel, D. E., Mattheisen, M., Mortensen, P. B., & Mors, O. (2015). Obsessive-Compulsive Disorder and Autism Spectrum Disorders: Longitudinal and Offspring Risk. *PLOS ONE*, *10*(11), e0141703. <u>https://doi.org/10.1371/journal.pone.0141703</u>; Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, *9*, 35. <u>https://doi.org/10.1186/1471-244X-9-35</u>; Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in Adults with Autism Spectrum Disorder: The Role of Depressive Symptomatology, Alexithymia, and Antidepressants. *Journal of Autism and Developmental Disorders*, *50*(10), 3585–3597. <u>https://doi.org/10.1007/s10803-020-04433-3</u>

6 Rumball, F., Happé, F., & Grey, N. (2020). Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. Autism Research, 13(12), 2122–2132. https://doi.org/10.1002/aur.2306

7 Brewin, C. R., Rumball, F., & Happé, F. (2019). Neglected causes of post-traumatic stress disorder. BMJ, 365, l2372. https://doi.org/10.1136/bmj.l2372

³ Mattila, M.-L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., Linna, S.-L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. L., & Moilanen, I. (2010). Comorbid Psychiatric Disorders Associated with Asperger Syndrome/High-functioning Autism: A Community- and Clinic-based Study. *Journal of Autism and Developmental Disorders*, 40(9), 1080–1093. https://doi.org/10.1007/s10803-010-0958-2

⁴ Hudson, C. C., Hall, L., & Harkness, K. L. (2019). Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: A Meta-Analysis. *Journal of Abnormal Child Psychology*, *47*(1), 165–175. <u>https://doi.org/10.1007/s10802-018-0402-1</u>

Social factors like bullying, abuse, loneliness, and social prejudices against autistic people can also contribute to mental health distress. Prejudice against autistic people—including negative stereotyping, ostracism, social rejection, and everyday discrimination—can lead to poorer mental health outcomes.⁸ For example...

- Autistic children and youth are more likely to be bullied than their nonautistic counterparts.⁹ Bullying is associated with higher rates of suicidal ideation and behavior in both disabled and nondisabled children and youth.¹⁰
- Autistic people are more likely to experience loneliness and social isolation than nonautistic people. Loneliness is associated with anxiety and depression in autistic people.¹¹
- According to a French study, 90% of autistic women (based on self-identification) are more likely to experience sexual abuse in childhood, compared with the 30% rate found in the general publication. This exposure to sexual violence left many research participants with PTSD.¹²

⁸ Botha, M., & Frost, D. M. (2020). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. Society and Mental Health, 10(1), 20–34. https://doi.org/10.1177/2156869318804297

⁹ Humphrey, N., & Hebron, J. (2015). Bullying of children and adolescents with autism spectrum conditions: A 'state of the field' review. *International Journal of Inclusive Education*, *19*(8), 845–862. <u>https://doi.org/</u> 10.1080/13603116.2014.981602

¹⁰ Holt, M. K., Vivolo-Kantor, A. M., Polanin, J. R., Holland, K. M., DeGue, S., Matjasko, J. L., Wolfe, M., & Reid, G. (2015). Bullying and Suicidal Ideation and Behaviors: A Meta-Analysis. *Pediatrics*, *135*(2), e496–e509. <u>https://doi.org/10.1542/peds.2014-1864</u>

¹¹ Hymas, R., Badcock, J. C., & Milne, E. (2022). Loneliness in Autism and Its Association with Anxiety and Depression: A Systematic Review with Meta-Analyses. *Review Journal of Autism and Developmental Disorders*. <u>https://doi.org/</u>
<u>10.1007/s40489-022-00330-w</u>; Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A
20-year study of suicide death in a statewide autism population. *Autism Research*, *12*(4), 658–666. <u>https://doi.org/</u>
<u>10.1002/aur.2076</u>

¹² Cazalis, F., Reyes, E., Leduc, S., & Gourion, D. (2022). Evidence that nine out of ten autistic women have been victims of sexual violence. Frontiers in Behavioral Neuroscience 2022 (6). <u>https://doi.org/10.3389/fnbeh.2022.852203</u>

• Many autistic people engage in "camouflaging," "masking," or otherwise intentionally hiding their autistic traits in an attempt to avoid discrimination, harm, or abuse. One study found that masking is connected to higher rates of anxiety in autistic adults.¹³

Tragically, autistic people are more likely to experience suicidality or attempt suicide than their neurotypical counterparts.¹⁴ Multiple variables correlate with this heightened risk of suicidality, including higher rates of major depression, unemployment, dissatisfaction with potentially abusive or substandard living arrangements, and the stress of camouflaging or masking.¹⁵ Moreover, autistic people with coexisting psychosocial disabilities, such as bipolar disorder or borderline personality disorder, may be of heightened risk for experiencing suicidality and dying by suicide. Bipolar disorder alone has one of the highest documented rates of completed suicides among people with psychosocial disabilities.¹⁶

RACE AND MENTAL HEALTH

Diagnosis rates for psychiatric conditions often vary between races and ethnicities, and some people of color are more likely to show signs of, or receive diagnoses for, psychosocial disabilities, including schizophrenia and psychosis, than are white people.

• Black and Latino/Latinx/Latine autistic people are more likely have diagnoses of schizophrenia than their white counterparts.¹⁷

¹⁵ Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, *9*(1), 42. <u>https://doi.org/10.1186/s13229-018-0226-4</u>

¹³ Hull, L., Levy, L., Lai, M.-C., Petrides, K. V., Baron-Cohen, S., Allison, C., Smith, P., & Mandy, W. (2021). Is social camouflaging associated with anxiety and depression in autistic adults? *Molecular Autism*, *12*(1), 13. <u>https://doi.org/10.1186/s13229-021-00421-1</u>

¹⁴ Cassidy, S., Au-Yeung, S., Robertson, A., Cogger-Ward, H., Richards, G., Allison, C., Bradley, L., Kenny, R., O'Connor, R., Mosse, D., Rodgers, J., & Baron-Cohen, S. (2022). Autism and autistic traits in those who died by suicide in England. *The British Journal of Psychiatry*, 1–9. <u>https://doi.org/10.1192/bjp.2022.21</u>; Kõlves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of Suicidal Behaviors Among Individuals With Autism Spectrum Disorder in Denmark. *JAMA Network Open*, *4*(1), e2033565. <u>https://doi.org/10.1001/jamanetworkopen.2020.33565</u>; Zahid, S., & Upthegrove, R. (2017). Suicidality in Autistic Spectrum Disorders: A Systematic Review. *Crisis*, *38*(4), 237–246. <u>https://doi.org/10.1027/0227-5910/a000458</u>

¹⁶ Miller, J. N., & Black, D. W. (2020). Bipolar Disorder and Suicide: A Review. *Current Psychiatry Reports*, *22*(2), 6. https://doi.org/10.1007/s11920-020-1130-0

¹⁷ Moens, J. (2022, January 19). Autism comorbidities reflect racial, ethnic disparities. *Spectrum*. <u>https://</u> www.spectrumnews.org/news/autism-comorbidities-reflect-racial-ethnic-disparities/

- South Africans are more likely to qualify for psychiatric diagnoses than Nigerians.¹⁸
- A German study found that people of color, especially Black and African Caribbean people, were more likely to have psychosis or subclinical symptoms of psychosis, and the risk of psychotic symptoms was connected to racism and the experience of immigration from non-Western countries.¹⁹
- Black and South Asian people in the United Kingdom are more likely to have psychosis than people of other racial backgrounds.²⁰ (Not only are people of color more likely to be diagnosed with psychosis, they are also more likely to receive forcible treatment for it.²¹)
- Of the six countries with the highest reported schizophrenia rates, half are in the Global South (Colombia, Bangladesh, and Sudan), while the rest are in the Global North (Austria, France, and Germany).²²
- Roma people in Scotland are more likely to have mental health difficulties than their white Scottish counterparts.²³

²¹ Buswell, G., Haime, Z., Lloyd-Evans, B., & Billings, J. (2021). A systematic review of PTSD to the experience of psychosis: Prevalence and associated factors. *BMC Psychiatry*, *21*(1), 9. <u>https://doi.org/10.1186/s12888-020-02999-x</u>

²² Our World in Data (2019). Schizophrenia prevalence, 2019. *Our World in Data*. Retrieved from <u>https://ourworldindata.org/grapher/schizophrenia-prevalence?tab=chart</u>

¹⁸ Williams, D. R., Herman, A., Stein, D. J., Heeringa, S. G., Jackson, P. B., Moomal, H., & Kessler, R. C. (2008). Twelvemonth mental disorders in South Africa: prevalence, service use and demographic correlates in the population-based South African Stress and Health Study. *Psychological medicine*, 38(2), 211–220. https://doi.org/10.1017/ S0033291707001420

¹⁹ Lazaridou, F. B., Schubert, S. J., Ringeisen, T., Kaminski, J., Heinz, A., & Kluge, U. (2022). Racism and psychosis: An umbrella review and qualitative analysis of the mental health consequences of racism. *European Archives of Psychiatry and Clinical Neuroscience*. <u>https://doi.org/10.1007/s00406-022-01468-8</u>

²⁰ McManus, S., Bebbington, P., Jenkins, R., & Brugha, T. (2016). *Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014: a survey carried out for NHS Digital by NatCen Social Research and the Department of Health Sciences, University of Leicester.* NHS Digital.; Mirza, A., Birtel, M. D., Pyle, M., & Morrison, A. P. (2019). Cultural Differences in Psychosis: The Role of Causal Beliefs and Stigma in White British and South Asians. *Journal of Cross-Cultural Psychology*, *50*(3), 441–459. <u>https://doi.org/10.1177/0022022118820168</u>

²³ Muir, K. (2022, June 24). Health Inequalities in the Gypsy, Roma and Traveller Community – How we are making change happen? *Public Health Scotland*. Retrieved 4 September 2022, from <u>https://publichealthscotland.scot/our-blog/</u>2022/june/health-inequalities-in-the-gypsy-roma-and-traveller-community-how-we-are-making-change-happen/

All these findings suggest that, as many community leaders and advocates have frequently argued, mental distress may be connected to the ongoing effects of systemic racism, colonialism, imperialism, and socioeconomic inequality.

Higher rates of suicide, suicide attempts, or suicidal thoughts occur among some racial and ethnic groups.

- Roma people are over six times as likely to die by suicide than are white Scots.²⁴
- Native/Indigenous peoples in North America, New Zealand, and Australia have higher rates of suicidal thoughts, suicide attempts, and completed suicides. In the United States, Native/Indigenous people have the highest rate of suicidal thoughts, and Native Hawaiians and Pacific Islanders specifically have the highest rate of suicide attempts.²⁵ First Nations people in Canada also have higher rates of suicidal ideation, attempts, and completed suicides compared with other ethnic and racial groups.²⁶ In Australia, the suicide rate among Indigenous peoples, including Torres Strait Islanders, is about twice the national average.²⁷ In New Zealand, Māori men have higher rates of suicide than other populations.²⁸
- The top 10 countries by reported suicide rate (number of suicides per 100,000) are predominantly non-European or Global South countries—Lesotho (72.4), Guyana (40.3), Eswatini [formerly known as Swaziland] (29.4), South Korea (28.6), Kiribati (28.3), Micronesia (28.2), Suriname (25.4), and South Africa (23.5). Lithuania and Russia are the only European countries on the list.²⁹ Although Uruguay did not make the top 10, its rate of

²⁶ Naherniak, B., Bhaskaran, J., Sareen, J., Wang, Y., & Bolton, J. M. (2019). Ambivalence About Living and the Risk for Future Suicide Attempts: A Longitudinal Analysis. *The Primary Care Companion for CNS Disorders*, *21*(2), 26619. <u>https://doi.org/10.4088/PCC.18m02361</u>

²⁷ Mindframe (2020). Reporting suicide and mental ill-health: a *Mindframe* resource for media professionals. Mindframe. <u>https://mindframemedia.imgix.net/assets/src/uploads/MF-Media-Professionals-DP-LR.pdf</u>

²⁴ Muir, K. (2022, June 24). Health Inequalities in the Gypsy, Roma and Traveller Community – How we are making change happen? *Public Health Scotland*. <u>https://publichealthscotland.scot/our-blog/2022/june/health-inequalities-in-the-gypsy-roma-and-traveller-community-how-we-are-making-change-happen/</u>

²⁵ Suicide Prevention Resource Center. (2020, October). Racial and Ethnic Disparities. Suicide Prevention Resource Center. <u>https://sprc.org/scope/racial-ethnic-disparities</u>

²⁸ Smith, M. (2022). Suicide Risk Assessments: A Scientific and Ethical Critique. *Journal of Bioethical Inquiry*, 19(3), 481–493. <u>https://doi.org/10.1007/s11673-022-10189-5</u>

²⁹ World Population Review (2023). Suicide rate by country 2023: countries with the highest suicide rates. World Population Review. <u>https://worldpopulationreview.com/country-rankings/suicide-rate-by-country</u>

21.2 suicides per 100,000 is still among the highest in the world. On the other hand, countries like Brazil, Papua New Guinea, Mexico, and Algeria have lower reported rates of suicide than the United States, France, and Canada.³⁰

In 2022, over 500 Japanese children and adolescents died by suicide—the highest rate on record for the country. Among the general population, 21,881 people died by suicide in 2022 —a 4.2% increase from 2021. Health problems were the prevailing cause for suicide among the general Japanese population, followed by family tensions and financial struggles.³¹

Some groups, on the other hand, have lower suicide rates than the national average, but suicide is on the rise among teenagers and young adults.

- Although the overall Black suicide rate in the United States is lower than that of other races, there has been an alarming increase in suicides among Black children and youth.³²
- Asian Americans have lower suicide rates than their white counterparts, but suicide is the leading cause of death among Asian Americans ages 15-24. Within this population, Chinese Americans are more likely to attempt or consider suicide than other Asian groups, including

³⁰ World Population Review (2023). Suicide rate by country 2023: countries with the highest suicide rates. World Population Review. <u>https://worldpopulationreview.com/country-rankings/suicide-rate-by-country</u>

³¹ Ishikawa, T. (2023, March 14). Suicides top 500 among young students for 1st time ever. *Asahi Shimbun*. <u>https://</u>www.asahi.com/ajw/articles/14861109

³² American Academy of Child & Adolescent Psychiatry. (2022, March). AACAP Policy Statement on Increased Suicide Among Black Youth in the U.S. American Academy of Child & Adolescent Psychiatry. <u>https://www.aacap.org/aacap/</u> <u>Policy_Statements/2022/AACAP_Policy_Statement_Increased_Suicide_Among_Black_Youth_US.aspx;</u> Caron, C., & James, J. (2021, November 18). Why Are More Black Kids Suicidal? A Search for Answers. *The New York Times*. <u>https://</u> <u>www.nytimes.com/2021/11/18/well/mind/suicide-black-kids.html</u>; Joe, S. (2018, October 5). Addressing Suicide among Black Americans. Suicide Prevention Resource Center. <u>https://www.sprc.org/news/addressing-suicide-among-black-americans</u>

Filipinos, Vietnamese, and other Asians.³³ Unfortunately, compared with other races, Asian Americans are the least likely to use mental health services.³⁴

On the other hand, some people living outside Europe and North America may have fewer mental health complaints than their Western counterparts—and often, culturally rooted forms of healing provide many of the same benefits as Western biomedical treatments.

- Based on data from 2017, the top 10 countries with the highest rates of reported depression are in North America or Europe: Ukraine, the United States, Estonia, Australia, Greece, Portugal, Belarus, Finland, and Lithuania. Only one country—Brazil—is in the Global South.³⁵ Meanwhile, the bottom 10 countries for reported depression were all in Asia and the Pacific Islands: the Solomon Islands, Papua New Guinea, Timor-Leste, Vanuatu, Kiribati, Tonga, Samoa, Laos, Nepal, and the Philippines.³⁶
- In a 1960s study conducted by the World Health Organization, Indians and Nigerians diagnosed with schizophrenia had better outcomes in comparison with peer cohorts of other racial and ethnic groups in the United States and United Kingdom, even though they received less formal psychiatric care.³⁷
- In South India, people with psychosis who attended a Hindu temple with expertise in supporting people with psychosocial disabilities described improvements in mental health

³³ Noor-Oshiro, A. (2021, April 23). Asian American young adults are the only racial group with suicide as their leading cause of death, so why is no one talking about this? *The Conversation*. <u>http://theconversation.com/asian-american-young-adults-are-the-only-racial-group-with-suicide-as-their-leading-cause-of-death-so-why-is-no-one-talking-about-this-158030; U.S. Department of Health and Human Services Office of Minority Health. (2021, May 19). Mental and Behavioral Health—Asian Americans—The Office of Minority Health. <u>https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&clvlid=54</u></u>

³⁴ Noor-Oshiro, A. (2021, April 23). Asian American young adults are the only racial group with suicide as their leading cause of death, so why is no one talking about this? *The Conversation*. <u>http://theconversation.com/asian-american-young-adults-are-the-only-racial-group-with-suicide-as-their-leading-cause-of-death-so-why-is-no-one-talking-about-this-158030</u>

³⁵ World Population Review (2023). Depression rates by country, 2023. *World Population Review*. Retrieved from https://worldpopulationreview.com/country-rankings/depression-rates-by-country

³⁶ World Population Review (2023). Depression rates by country, 2023. *World Population Review*. Retrieved from https://worldpopulationreview.com/country-rankings/depression-rates-by-country

³⁷ Fernando, S. (2019). Developing mental health services in the global south. *International Journal of Mental Health*,
48. DOI: https://doi.org/10.1080/00207411.2019.1706237

at a similar rate to those who used biomedical treatments.³⁸ In another Indian study, people who used Hindu, Islamic, or Christian religious healing or Ayurvedic medicine were just as likely to benefit from these modalities as those who used biomedical treatments.³⁹

THE INTERSECTION OF AUTISM, RACE, AND MENTAL HEALTH

Few studies exist that examine the relationship between autism, race, and mental health, but those that do suggest that autistic people of color are more likely to have psychosocial disabilities than their white autistic counterparts.⁴⁰ For example, Williams et al. found that Black transition-aged youth ages 16 to 26 were more likely to have depressive symptoms than their white counterparts.⁴¹ They were also more likely to have major depression, though the results were not statistically significant.

In the next section, "Supporting the Mental Well-Being of Autistic People of Color," we provide a list of research questions that scholars can use to learn more about the mental well-being of autistic people of color, and ways that policymakers can combat mental health inequities.

Supporting the Mental Well-Being of Autistic People of Color

The Autistic People of Color Fund urges policymakers and practitioners to use the principles of disability justice to support autistic people of color with psychiatric disabilities. Members of Sins Invalid, a radical disability performance and political project, identified ten principles of disability justice work: intersectionality, leadership of the most impacted, anti-capitalist politics, cross-movement solidarity, recognizing wholeness, sustainability, commitment to cross-disability

³⁸ Fernando, S. (2019). Developing mental health services in the global south. *International Journal of Mental Health*,
48. DOI: https://doi.org/10.1080/00207411.2019.1706237

³⁹ Fernando, S. (2019). Developing mental health services in the global south. *International Journal of Mental Health*,
48. DOI: https://doi.org/10.1080/00207411.2019.1706237

⁴⁰ Williams, E.-D. G., Smith, M. J., Sherwood, K., Lovelace, T. S., & Bishop, L. (2022). Brief Report: Initial Evidence of Depressive Symptom Disparities among Black and White Transition Age Autistic Youth. *Journal of Autism and Developmental Disorders*, *52*(8), 3740–3745. <u>https://doi.org/10.1007/s10803-021-05242-y</u>

⁴¹ Williams, E.-D. G., Smith, M. J., Sherwood, K., Lovelace, T. S., & Bishop, L. (2022). Brief Report: Initial Evidence of Depressive Symptom Disparities among Black and White Transition Age Autistic Youth. *Journal of Autism and Developmental Disorders*, *52*(8), 3740–3745. <u>https://doi.org/10.1007/s10803-021-05242-y</u>

solidarity, interdependence, collective access, and collective liberation.⁴² All our recommendations start from and are informed by these principles.

We call for a comprehensive understanding of mental health that does not reduce psychosocial disability to chemical imbalances or pathology. Policymakers and clinicians must address the social, economic, and cultural factors that cause, contribute to, and exacerbate depression, anxiety, and other psychiatric disabilities.⁴³ Crisis hotlines and cognitive-behavioral therapy will not resolve depression and anxiety caused, for instance, by financial stress from housing and food insecurity.

Instead, policymakers must provide assistance with rent and mortgages, affordable housing, expanded benefit programs, debt forgiveness and relief (including consumer debt and student loans), and direct job placement. Treating depression, anxiety, and other psychiatric conditions as though they were merely individual problems erases the material and cultural conditions that harm people's mental and spiritual well-being.⁴⁴ We cannot in good conscience tell people that their lives are worth living while we leave them in misery.

We call for alternatives to incarcerating people experiencing mental distress. As staunch abolitionists, we cannot support any system in which people are forcibly removed from their family, friends, and communities in the name of recovery. Incarceration is not limited to prisons and jails; it also includes psychiatric hospitals, as well as locked psychiatric wards in general-purpose hospitals.

We call for a radical reimagining of the mental healthcare system to support autistic people of color. We urge policymakers, program directors, and advocates to consider the following solutions:

SUPPORTING AUTISTIC PEOPLE OF COLOR IN MENTAL HEALTH CRISES

Autistic people of color deserve support in their most vulnerable moments, including periods of suicidal depression and altered states like psychosis and delirium. To do this well, policymakers and service providers must use methods that acknowledge people's dignity, consider the effects of lifetime and historical trauma, reject ostracism, and eschew incarceration.

⁴² Sins Invalid (2015, September 17). 10 Principles of Disability Justice. Sins Invalid. <u>https://www.sinsinvalid.org/blog/</u>10-principles-of-disability-justice

⁴³ Barnhorst, A. (2019, April 27). Opinion | The Empty Promise of Suicide Prevention. *The New York Times*. <u>https://</u>www.nytimes.com/2019/04/26/opinion/sunday/suicide-prevention.html

⁴⁴ Carr, D. (2022, September 20). Mental Health Is Political. *The New York Times*. <u>https://www.nytimes.com/</u>2022/09/20/opinion/us-mental-health-politics.html

- Remove the police from crisis response. In a mental health crisis, the last thing autistic people of color need is the threat of police violence. Between 2015 and 2021, nearly one-quarter of police-shooting victims were undergoing—or were thought to be undergoing—a mental health crisis.⁴⁵ Law-enforcement-led responses to mental health crises can result in trauma, violence, lost jobs, and other adverse consequences.⁴⁶ Fortunately, some jurisdictions are moving toward less dangerous practices. The state of Illinois shows a way forward through its Community Emergency Services and Supports Act, or CESSA. Passed in 2021, CESSA prohibits the police from responding to nonviolent, noncriminal "mental and behavioral health crises."⁴⁷ Under the law, emergency calls made to 911, 311, and other emergency numbers will be redirected to the state 988 number.
- Work to counter systemic bias against autistic people of color with psychiatric disabilities. Racially and ethnically marginalized people in both Western and non-Western countries are more likely to encounter bias for having depression and anxiety than are members of dominant racial and ethnic groups.⁴⁸
- Find alternatives to incarceration for autistic people of color with psychosocial disabilities. People with psychosocial disabilities in the United States and United Kingdom are overrepresented in prisons, and Black people with psychiatric disabilities are more likely

⁴⁵ Kim, M. E., Chung, M., Hassan, S., & Ritchie, A. J. (2021). *Defund the Police—Invest in Community Care: A Guide to Alternative Mental Health Responses*. Interrupting Criminalization. <u>https://static1.squarespace.com/static/</u> 5ee39ec764dbd7179cf1243c/t/60ca7e7399f1b5306c8226c3/1623883385572/Crisis+Response+Guide.pdf

⁴⁶ Bossing, L. (2022). A New Day or More of the Same? Our Hopes & Fears for 988 (and 911). Bazelon Center for Mental Health Law. <u>https://secureservercdn.net/198.71.233.69/d25.2ac.myftpupload.com/wp-content/uploads/2022/06/A-New-Day-or-More-of-the-Same-Our-Hopes-Fears-for-988-and-911.pdf</u>

⁴⁷ Huff, C. (n.d.). CESSA: Community Emergency Services and Support Act. *Access Living*. Retrieved 30 September 2022, from <u>https://www.accessliving.org/defending-our-rights/racial-justice/community-emergency-services-and-support-act-cessa/</u>

⁴⁸ Eylem, O., de Wit, L., van Straten, A., Steubl, L., Melissourgaki, Z., Danışman, G. T., de Vries, R., Kerkhof, A. J. F. M., Bhui, K., & Cuijpers, P. (2020). Stigma for common mental disorders in racial minorities and majorities a systematic review and meta-analysis. *BMC Public Health*, *20*(1), 879. https://doi.org/10.1186/s12889-020-08964-3

to be incarcerated than their white counterparts.⁴⁹ In a study of Los Angeles county jails, Black people were overrepresented among those receiving mental health services.⁵⁰ Autistic men are also overrepresented in prisons.⁵¹ Instead of jailing people who need support with their mental health, policymakers and organizations can use other methods, like intensive outpatient treatment or treatment courts. For example, in a number of U.S. jurisdictions, including the state of California and Oklahoma City, judges use "mental health courts" where nonviolent offenders with mental health conditions are offered coordinated treatment programs and supports instead of incarceration.⁵² These mental health courts should allow people to exercise autonomy and receive care that is culturally appropriate and thoughtful.

- When supporting autistic people of color who are experiencing suicidal ideation, consider the complex causes that lead to suicidal ideation and attempts. Suicidal urges often arise from economic pressures, ableism, racism, misogyny, transphobia, homophobia, or other systemic factors that cannot be solved easily. Project LETS, a radical mental health advocacy group, offers <u>a guide</u> to avoiding common mistakes when supporting people who are contemplating suicide or self-harm.
- Use trauma-informed methods, including peer crisis support and peer-directed respite centers, to support people undergoing mental health crises. Hospitalization, restraints, and seclusion can cause and contribute to stress and trauma.⁵³

⁵¹ Hess, P. (2020, November 11). Autism behind bars. *Spectrum*. <u>https://www.spectrumnews.org/features/deep-dive/</u> autism-behind-bars/

⁵² Bailey, D.S. (2003). Alternatives to incarceration. *Monitor on Psychology*, July/August 2003, 34(7). Retrieved from https://www.apa.org/monitor/julaug03/alternatives

⁵³ Lu, W., Mueser, K. T., Rosenberg, S. D., Yanos, P. T., & Mahmoud, N. (2017). Posttraumatic Reactions to Psychosis: A Qualitative Analysis. *Frontiers in Psychiatry*, *8*, 129. <u>https://doi.org/10.3389/fpsyt.2017.00129</u>

⁴⁹ American Psychiatric Association. (2017). Mental Health Disparities: African Americans. American Psychiatric Association. <u>https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-African-Americans.pdf;</u> Substance Abuse and Mental Health Services Administration. (2022, March 2). About Criminal and Juvenile Justice. Substance Abuse and Mental Health Services Administration. <u>https://www.samhsa.gov/criminal-juvenile-justice/about;</u> Carroll, H. (2016). Serious Mental Illness Prevalence in Jails and Prisons. Treatment Advocacy Center. <u>https://www.treatmentadvocacycenter.org/evidence-and-research/learn-more-about/3695</u>; Ramesh, R. (2014, November 13). UK's mentally ill people more likely to be found in jail than hospital. *The Guardian*. <u>https://www.theguardian.com/society/2014/nov/13/mentally-disturbed-prisons-matthew-williams-health-services</u>

⁵⁰ Appel, O., Stephens, D., Shadravan, S. M., Key, J., & Ochoa, K. (2020). Differential Incarceration by Race-Ethnicity and Mental Health Service Status in the Los Angeles County Jail System. *Psychiatric Services*, *71*(8), 843–846. <u>https://doi.org/10.1176/appi.ps.201900429</u>

- Support crisis hotlines that do not contact the police. For instance, hotlines like 988 will work with the police if someone is in an acute suicidal crisis, but the Trans Lifeline does not make nonconsensual emergency calls.⁵⁴
- Support, train, and fund non-police mobile crisis teams, similar to the <u>CAHOOTS</u> <u>program</u> in Eugene, Oregon.⁵⁵ Wellness checks by law enforcement are risky for people of color, since they are more likely to suffer from police violence than white people are.⁵⁶ People with psychiatric disabilities and their nondisabled counterparts face similar risks.⁵⁷
- Respect the autonomy and privacy of people with psychiatric disabilities by avoiding nonconsensual interventions whenever possible. As abolitionists, we oppose the use of forced hospitalization as a suicide-prevention method. Instead of incarceration, practitioners should use restorative methods that affirm people's dignity and human rights. Involuntary psychiatric holds are intended to dissuade or prevent people from dying by suicide, but the perception of coercion may increase the risk of suicide attempts after discharge.⁵⁸ Also, marginalized groups, such as Māori and other Indigenous peoples, are more likely to be subjected to forcible treatment.⁵⁹ This is not the only problem with forced psychiatric hospitalization: uninsured and underinsured people in psychiatric hospitals can receive a hefty bill upon discharge.⁶⁰ Since debt and financial stress are risk factors for suicide,

⁵⁶ Mubarak, E., Turner, V., Shuman, A. G., Firn, J., & Price, D. (2022). Promoting Antiracist Mental Health Crisis Responses. AMA Journal of Ethics, 24(8), 788–794. <u>https://doi.org/10.1001/amajethics.2022.788</u>

⁵⁷ Mubarak, E., Turner, V., Shuman, A. G., Firn, J., & Price, D. (2022). Promoting Antiracist Mental Health Crisis Responses. *AMA Journal of Ethics*, *24*(8), 788–794. <u>https://doi.org/10.1001/amajethics.2022.788</u>

⁵⁸ Jordan, J. T., & McNiel, D. E. (2020). Perceived Coercion During Admission Into Psychiatric Hospitalization Increases Risk of Suicide Attempts After Discharge. *Suicide and Life-Threatening Behavior*, 50(1), 180–188. <u>https://doi.org/</u> <u>10.1111/sltb.12560</u>

⁵⁹ Smith, M. (2022). Suicide Risk Assessments: A Scientific and Ethical Critique. *Journal of Bioethical Inquiry*, *19*(3), 481–493. <u>https://doi.org/10.1007/s11673-022-10189-5</u>

⁶⁰ Bossing, L. (2022). *A New Day or More of the Same? Our Hopes & Fears for 988 (and 911)*. Bazelon Center for Mental Health Law. <u>https://secureservercdn.net/198.71.233.69/d25.2ac.myftpupload.com/wp-content/uploads/2022/06/A-New-Day-or-More-of-the-Same-Our-Hopes-Fears-for-988-and-911.pdf</u>

⁵⁴ Way, K. (2022, July 25). 988 Has a Transparency Problem. *Vice*. <u>https://www.vice.com/en/article/g5vq97/988-national-suicide-prevention-lifeline-not-cop-free</u>

⁵⁵ Carroll, J. J., El-Sabawi, T., Fichter, D., Pope, L. G., Rafla-Yuan, E., Compton, M. T., & Watson, A. (2021, September 8). The Workforce For Non-Police Behavioral Health Crisis Response Doesn't Exist—We Need To Create It. *Health Affairs Forefront*. <u>https://doi.org/10.1377/forefront.20210903.856934</u>

nonconsensual interventions may exacerbate the problem they ostensibly address.⁶¹ The fear of forced hospitalization may prevent people with suicidal thoughts or urges from seeking help in the first place.⁶² Forced hospitalization is also harmful in other types of psychosocial crises, including acute psychosis. Although many jurisdictions have moved toward using noncoercive methods to support people experiencing extreme or altered states, this transition is incomplete.⁶³

Be wary of policies and campaigns that advocate for replacing prisons with psychiatric institutionalization. For example, California recently adopted a new program, CARE Courts, that will force "noncompliant" homeless people into long-term psychiatric treatment.⁶⁴ The mayor of New York City, Eric Adams, has also issued an order to hospitalize people who are "too mentally ill to care for themselves," even if they are nonviolent.⁶⁵ Although psychiatric hospitals are a superficial improvement over jails and prisons, both institutions hold people captive and strip them of their human rights.⁶⁶ In *Decarcerating Disability: Deinstitutionalization and Prison Abolition*, Liat Ben-Moshe writes, "… incarceration is not just a space or locale but a logic of state coercion and segregation of difference. And as we showed, it is a racist, colonial, gendered logic at its core."⁶⁷ We urge governments to question the use of forced treatment to support homeless people with psychiatric disabilities.

⁶³ Gooding, P., McSherry, B., & Roper, C. (2020). Preventing and reducing 'coercion' in mental health services: An international scoping review of English-language studies. *Acta Psychiatrica Scandinavica*, *142*(1), 27–39. <u>https://doi.org/10.1111/acps.13152</u>

⁶⁴ Har, J., & Beam, A. (2022, September 1). CA Lawmakers Approve Mental Health Care Plan for Homeless. *NBC Bay Area*. https://www.nbcbayarea.com/news/california/california-mental-health-care-plan-homeless-people/2990592/; Luis, C. (2022, August 9). Forced Treatment Isn't What Unhoused People Need. *The Nation*. <u>https://</u> www.thenation.com/article/society/california-care-courts-homelessness/

⁶⁵ Newman, A., & Fitzsimmons, E. G. (2022, November 29). New York City to Involuntarily Remove Mentally Ill People From Streets. *The New York Times*. <u>https://www.nytimes.com/2022/11/29/nyregion/nyc-mentally-ill-involuntary-custody.html</u>

⁶⁶ Ben-Moshe, L. (2020). *Decarcerating disability: Deinstitutionalization and prison abolition*. University of Minnesota Press.

⁶⁷ Ben-Moshe, L. (2020). *Decarcerating disability: Deinstitutionalization and prison abolition*. University of Minnesota Press.

⁶¹ Trans Lifeline. (n.d.). Fact Sheet: Transgender Callers and Crisis Hotlines. Trans Lifeline. Retrieved 29 August 2022, from https://translifeline.org/safe-hotlines/fact-sheet/

⁶² Wang, D. W. L., & Colucci, E. (2017). Should compulsory admission to hospital be part of suicide prevention strategies? *BJPsych Bulletin*, *41*(3), 169–171. https://doi.org/10.1192/pb.bp.116.055699

Homeless people need no-strings-attached supportive housing and responsive outpatient care, not psychiatric incarceration.

• Fund and promote noncoercive, peer-led, neurodiversity-affirming alternatives to psychiatric hospitalization. Peer-run respite centers, like <u>Afiya</u> in Northampton, Massachusetts, offer round-the-clock support for people with psychiatric disabilities without forcing them to leave their dignity at the door. Afiya receives funding from the Massachusetts Department of Mental Health.

PROVIDING ACCESSIBLE MENTAL HEALTH SERVICES AND COMMUNITY SUPPORT

Mental health services and community support programs should be accessible for autistic people, including autistic people of color. We use "accessibility" broadly to mean cognitive accessibility, emotional accessibility, cultural accessibility, and financial accessibility.

- Train mental health workers about autism and how autistic self-expression can affect the way people perceive our mental health. Autistic people may not express our psychological distress in ways that therapists recognize.
- Focus on mental health for autistic people in schools, starting at a young age. Anxiety, for example, can occur in school-aged autistic children.⁶⁸ Ensure, too, that schools can help families identify community resources for food, housing, financial support, and more, since socioeconomic stress can contribute to mental ill-health.
- Train counseling staff in colleges and universities to identify depression and other psychiatric conditions in autistic people.
- Train professionals to identify how forms of psychological distress, such as depression, manifest in different cultures.
- Consider combining traditional healing practices with biomedical interventions.
- Talk about mental health conditions in ways that reflect people's cultural background. In many non-Western cultures, indigenous classifications may correspond with or supplant psychiatric labels. For instance, in the Buganda language, schizophrenia is called *eddalu* or

⁶⁸ Mattila, M.-L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., Linna, S.-L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. L., & Moilanen, I. (2010). Comorbid Psychiatric Disorders Associated with Asperger Syndrome/High-functioning Autism: A Community- and Clinic-based Study. *Journal of Autism and Developmental Disorders*, 40(9), 1080–1093. <u>https://doi.org/10.1007/s10803-010-0958-2</u>

ilalu, and mania is called *kazoole*.⁶⁹ Yoruba native healers "use both etiological *[cause-based]* and symptom-logical concepts" to identify mental health conditions, including psychosis (called *were* in Yoruba). Moreover, countries in the Global South often have indigenous support systems that perform just as well as, or better than, North American or European systems—for instance, a study found that people in India and Nigeria with schizophrenia diagnoses were found to have better outcomes than Western counterparts.⁷⁰ Unfortunately, well-intentioned western nongovernmental and supranational organizations often try to impose Western models of "mental illness"—a form of neocolonialism or the white-savior complex—on these communities.⁷¹ For example, the World Health Organization claims to deliver mental healthcare using "culturally appropriate" methods, but its guidelines are still predicated on a Western biomedical model that may not match the cultural expectations or values of low- and middle-income countries.⁷²

- Support the family and friends of people with psychosocial disabilities, since community support is a crucial element in recovery. For instance, the YouBelong program in Uganda encourages family members to be "active agents of mental health care and central to recovery plans."⁷³ Family involvement is woven throughout the services and treatment plans that participants receive.
- Teach mental health practitioners to identify coexisting psychiatric conditions, such as depression, anxiety, OCD, or bipolar disorder, in autistic people.
- Increase the affordability of mental healthcare. A Danish study found that making therapy more financially accessible by eliminating copayments was associated with lower suicide rates

⁶⁹ Abbo, C. (2011). Profiles and outcome of traditional healing practices for severe mental illnesses in two districts of Eastern Uganda. *Global Health Action*, 4(0). doi:10.3402/gha.v4i0.7717

⁷⁰ Fernando, S. (2014). *Mental Health Worldwide: Culture, Globalization and Development*. Hampshire, UK; Palgrave Macmillan.

⁷¹ Fernando, S. (2014). *Mental Health Worldwide: Culture, Globalization and Development*. Hampshire, UK; Palgrave Macmillan.

⁷² Cox, N. & Webb, L. (2015). Poles apart: does the export of mental health expertise from the Global North to the Global South represent a neutral relocation of knowledge and practice? *Sociology of Health and Illness: a journal of medical sociology*. 35(5), pp. 683–697. DOI: 10.1111/1467-9566.12230

⁷³ YouBelong Uganda (2022, February 25). Learning from the Global South: Insights from YouBelong Uganda, in mental health innovations. YouBelong Uganda. <u>https://youbelongcommunity.org/learning-from-the-global-south-insights-from-youbelong-uganda-in-mental-health-innovations/</u>

among adolescents.⁷⁴ People were also more likely to go to therapy more frequently, thereby increasing their level of support. To increase the affordability of mental healthcare, governments can pass legislation to ensure that insurance reimbursements for therapy and psychiatry are equivalent to those paid to other healthcare practitioners.

- Provide comprehensive mental health support to autistic refugees and immigrants.
- Ensure that mental health services are available near autistic people of color. In the United States, health services, including medical and mental health clinics, are more likely to be in predominantly white neighborhoods.⁷⁵
- Fund and support community-based programs for people with psychosocial disabilities especially ones led by community members. For example, Women's Circles in rural Guatemalan villages bring Indigenous women together to support each other through camaraderie and mutual aid.⁷⁶ In Zimbabwe, the Friendship Bench program provides community support and cognitive-behavioral therapy that rely on indigenous concepts of psychosocial disability.⁷⁷
- Recruit, hire, train, and retain more psychiatrists, therapists, psychologists, and clinical social workers of color. A more diverse workforce will be better equipped to understand psychological distress that is connected to years of generational trauma from systemic racism.
- Make workplaces, doctors' offices, hospitals, and other public spaces accessible to autistic people. Since pretending to be neurotypical can increase anxiety levels, it's important to ensure that autistic people have the space to be who we are. Some examples include, offering places to recuperate, providing low-noise offices, allowing employees to take more frequent breaks, giving instructions in writing, prompting and cueing, and more.
- Work with activists and professionals in lower-income countries to support the mental health needs of people with psychiatric disabilities. All this work must be led by people in

⁷⁴ Kruse, M., Olsen, K. R., & Skovsgaard, C. V. (2022). Co-payment and adolescents' use of psychologist treatment: Spill over effects on mental health care and on suicide attempts. *Health Economics*. <u>https://doi.org/10.1002/hec.4582</u>

⁷⁵ Mensah, M., Ogbu-Nwobodo, L., & Shim, R. S. (2021). Racism and Mental Health Equity: History Repeating Itself. *Psychiatric Services*, *72*(9), 1091–1094. <u>https://doi.org/10.1176/appi.ps.202000755</u>

⁷⁶ Asociación de Mujeres de Altiplano (n.d.). Institutional methodology. *Asociación de Mujeres de Altiplano*. Retrieved
 27 August 2023, from https://amaguate.org/womens-circles

⁷⁷ Friendship Bench (n.d). https://www.friendshipbenchzimbabwe.org/about-us

these countries, even if they are receiving financial aid or aid in kind from wealthier countries or international nongovernmental organizations. When people in lower-income countries lead the conversation, organizations can avoid neo-imperialism or the white-savior mentality.

- Create spaces where autistic people of color can talk freely about their mental health without ostracism, stereotyping, or fear of forced treatment. Social isolation can exacerbate the effects of psychiatric disability—and even jeopardize physical health.⁷⁸ People find healing in community. A promising model exists in <u>Alternatives to Suicide</u> groups, which allow participants to discuss suicidal thoughts and urges without the threat of forced hospitalization, police intervention, or other nonconsensual suicide-prevention methods.
- Provide comprehensive reentry support to people who are leaving prisons, jails, or psychiatric hospitals. This support can include employment programs, individual therapy, education, one-on-one peer support, therapy groups, guaranteed income support, and more. For example, <u>REBUILD</u> offers grants to formerly incarcerated people of color who are reentering mainstream society, and Recovery Learning Communities and other peer-support centers often offer <u>peer bridger programs</u>, which connect people to community resources after discharge from a psychiatric hospital.

BUILDING AN EVIDENCE BASE TO SUPPORT THE MENTAL HEALTH OF AUTISTIC PEOPLE OF COLOR

Audre Lorde once said, "We do not live single-issue lives." And since we do not live single-issue lives, we cannot be described with single-issue studies. Although several studies exist that examine the relationship between race and mental health—or autism and mental health, for that matter—few explore the intersections of race, autism, and mental health. We encourage researchers to investigate the intersections between autism, race, and mental health. These studies must include autistic people of color as principal investigators, research staff, and participants. We recommend using the principles of <u>Participatory Action Research</u>. The <u>Society for Community Research</u>, a division of the American Psychological Association, conducts collaborative research with a focus on social justice, human rights, and diversity.

In this section, we offer advice for individual researchers and research organizations, as well as principles for researchers and funders who want to better understand the intersections between autism, race, and mental health.

⁷⁸ Novotney, A. (2019). The risks of social isolation. American Psychological Association. Retrieved 22 September 2022, from <u>https://www.apa.org/monitor/2019/05/ce-corner-isolation</u>

For individual researchers and research teams

These are examples of studies that individual researchers (e.g., doctoral students, independent researchers, think tank staff) can use to learn more about autism, race, and mental health.

- Conduct thematic analyses of autistic writers' experiences of psychiatric disabilities. These analyses should be racially and culturally inclusive.
- Conduct research about mental health supports in the Global South that are just as effective as, or more effective than, standard biomedical treatments in Western countries.
- Use qualitative and quantitative studies to learn about the experiences of autistic people of color receiving crisis services, including emergency-department visits, psychiatric hospitalization, mobile crisis teams, and emergency hotlines.
- Conduct qualitative research on autistic people who have multiple co-occurring psychosocial disabilities, such as obsessive-compulsive disorder and borderline personality disorder. These studies should oversample people of color, people of lower socioeconomic status, and those assigned female at birth.
- Conduct a study about autism and suicidality, focusing on the reasons, both concrete and abstract, for autistic people to contemplate ending their lives. Autistic people of color should be oversampled.
- Study the efficacy of crisis hotlines that avoid working with the police.
- Conduct prevalence studies that use nationally representative population surveys.
- Conduct qualitative studies using semistructured interviews and other methods. These interviews should include autistic people of color, their families and friends, therapists, psychiatrists, and other supporters.

For research organizations (including universities, nonprofits, and grassroots community organizations)

Larger research organizations, such as universities, think tanks, and nonprofits, can use these suggestions to build a stronger evidence base.

• Establish a research center that focuses on autistic people's mental health, with a particular focus on the needs of autistic people of color.

- Develop a survey to learn about practitioners' experience working with autistic people with psychiatric disabilities, with a focus on autistic people of color. Specifically, it can ask about any training they've received, anything they've learned on the job, and things that they would like to learn to become better practitioners.
- Develop national surveys of autistic adults that include questions about race and mental health conditions. These surveys should (a) include options for both gender identity and sex assigned at birth and (b) disaggregate racial and ethnic groups, so that groups (e.g., Asians) aren't treated as monoliths. Researchers can use the findings to identify correlations and develop support systems. These studies should oversample people of color, people assigned female at birth, people of lower socioeconomic status, and others who are traditionally underrepresented in autism studies.⁷⁹
- Create international surveys of autistic adults that oversample people living in non-Western countries.
- Develop mental health scales that include the personal experiences and cultural backgrounds of autistic people of color.

Principles for Researchers and Funders

- For each large-scale study (e.g., an international survey), create advisory boards of autistic people of color who can guide research studies and ensure that the findings truly benefit our communities.
- Ensure that autistic researchers of color can receive funding, support, and publicity for their research.

PROMOTING AUTISTIC PEOPLE OF COLOR'S MENTAL WELL-BEING BY RECOGNIZING SYSTEMIC INFLUENCES ON MENTAL HEALTH

Supporting autistic people of color's mental well-being must consider the effects of generational trauma, economic inequality, workplace discrimination, linguistic oppression, racial prejudice, imperialism, colonialism, and other injustices. It is not enough to treat our psychological distress as a "chemical imbalance." Mental health is political.

⁷⁹ Jones, D. R., & Mandell, D. S. (2020). To address racial disparities in autism research, we must think globally, act locally. *Autism, 24*(7), 1587–1589. https://doi.org/10.1177/1362361320948313; D'Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline. *Autism Research*, 15(10), 1929–1940. https://doi.org/10.1002/aur.2795

• Increase financial support for people with psychiatric disabilities, and ensure that mental health services are well funded. Financial difficulties increase the likelihood of depression and anxiety—and unemployment, debt, homelessness, and poverty are all associated with a higher risk of psychological distress, suicidal thoughts, and attempted suicides.⁸⁰ In one study, autistic adults who lost their jobs during the COVID-19 pandemic experienced worsened symptoms of depression.⁸¹ Since racism and ableism reduce the economic prospects of autistic people of color, it is likely that they are more likely to experience depression connected to their straitened circumstances. In the United States, low-income Black and Latino/x/e people are twice as likely to report psychological distress than Black people with higher incomes.⁸² In the United Kingdom, draconian benefit-determination processes have been associated with nearly 600 suicides and over 200,000 self-reported cases of mental distress.⁸³ Likewise, more than 25,000 people in India died by suicide over debt or unemployment in 2018, 2019, and 2020.⁸⁴ Despite the evidence connecting economic distress with psychological distress, neoliberal models of mental health obscure the

⁸⁰ Elbogen, E. B., Lanier, M., Montgomery, A. E., Strickland, S., Wagner, H. R., & Tsai, J. (2020). Financial Strain and Suicide Attempts in a Nationally Representative Sample of US Adults. *American Journal of Epidemiology*, *189*(11), 1266– 1274. <u>https://doi.org/10.1093/aje/kwaa146</u>; Zeira, A. (2022). Mental Health Challenges Related to Neoliberal Capitalism in the United States. *Community Mental Health Journal*, *58*(2), 205–212. <u>https://doi.org/10.1007/s10597-021-00840-7</u>; Manning, J. (2020, May 28). Why do people die by suicide? Mental illness isn't the only cause – social factors like loneliness, financial ruin and shame can be triggers. *The Conversation*. Retrieved 28 August 2022, from <u>http://</u> <u>theconversation.com/why-do-people-die-by-suicide-mental-illness-isnt-the-only-cause-social-factors-like-loneliness-financial-ruin-and-shame-can-be-triggers-131744</u>

⁸¹ Taylor, J. L., Adams, R. E., Pezzimenti, F., Zheng, S., & Bishop, S. L. (2022). Job loss predicts worsening depressive symptoms for young adults with autism: A COVID-19 natural experiment. *Autism Research*, *15*(1), 93–102. <u>https://doi.org/10.1002/aur.2621</u>

⁸² U.S. Department of Health and Human Services Office of Minority Health. (2021, May 20). Mental and Behavioral Health—Hispanics—The Office of Minority Health. The Office of Minority Health. <u>https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=69</u>; U.S. Department of Health and Human Services Office of Minority Health. (2021, May 18). Mental and Behavioral Health—African Americans. <u>https://www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=4&lvlid=24</u>;

⁸³ Recovery in the Bin, Edwards, B. M., Burgess, R., and Thomas, E. (2019, September). Neorecovery: A survivor led conceptualisation and critique [Transcript]. Keynote presented at the 25th International Mental Health Nursing Research Conference, The Royal College of Nursing, London, UK. https://recoveryinthebin.org/neorecovery-a-survivor-led-conceptualisation-and-critique-mhrn2019/

⁸⁴ Murali, M. (2022, February 10). 25,000 suicides linked to debt, jobs in three years: Govt in Rajya Sabha. *Hindustan Times*. <u>https://www.hindustantimes.com/india-news/25000-suicides-linked-to-debt-jobs-in-three-years-govt-in-rajya-sabha-101644432925249.html</u>

cultural, economic, and social contributors to psychiatric disability, including depression.⁸⁵ Neoliberalism, a socioeconomic policy that promotes deregulation, privatization, and the gutting of welfare states, favors a focus on individual responsibility over collective action.⁸⁶ Studies have connected mental ill-health to neoliberal cuts to public services; in one study, austerity policies were shown to lead to an increase of psychiatric diagnoses in the United States and the United Kingdom.⁸⁷ Recovery in the Bin, a British psychiatric survivors' group, calls the unholy alliance between neoliberalism and psychiatric treatment "neorecovery."⁸⁸

• Provide multilingual, multicultural mental health services. We should be able to talk about our lives and needs in our own languages with people who understand us. People from different regions and cultures may not understand psychiatric disability and mental distress the same way—for example, some cultures may have their own categories of mental distress that don't map onto conventional diagnostic categories.⁸⁹ Mental health services should consider the history of oppression and marginalization that people of color have experienced, since even services ostensibly designed for us can minimize the effects of colonialism, imperialism, slavery, genocide, and other generational traumas on our psyches.

⁸⁵ Recovery in the Bin, Edwards, B. M., Burgess, R., and Thomas, E. (2019, September). *Neorecovery: A survivor led conceptualisation and critique* [Transcript]. Keynote presented at the 25th International Mental Health Nursing Research Conference, The Royal College of Nursing, London, UK. <u>https://recoveryinthebin.org/neorecovery-a-survivor-led-conceptualisation-and-critique-mhrn2019/</u>

⁸⁶ Recovery in the Bin, Edwards, B. M., Burgess, R., and Thomas, E. (2019, September). *Neorecovery: A survivor led conceptualisation and critique* [Transcript]. Keynote presented at the 25th International Mental Health Nursing Research Conference, The Royal College of Nursing, London, UK. <u>https://recoveryinthebin.org/neorecovery-a-survivor-led-conceptualisation-and-critique-mhrn2019/</u>

⁸⁷ Zeira, A. (2022). Mental Health Challenges Related to Neoliberal Capitalism in the United States. *Community Mental Health Journal*, *58*(2), 205–212. <u>https://doi.org/10.1007/s10597-021-00840-7</u>; Cummins, I. (2018). The Impact of Austerity on Mental Health Service Provision: A UK Perspective. *International Journal of Environmental Research and Public Health*, 15(6), 1145. <u>https://doi.org/10.3390/ijerph15061145</u>; Stuckler, D., Reeves, A., Loopstra, R., Karanikolos, M., & McKee, M. (2017). Austerity and health: The impact in the UK and Europe. *European Journal of Public Health*, 27(suppl_4), 18–21. <u>https://doi.org/10.1093/eurpub/ckx167</u>

⁸⁸ Recovery in the Bin, Edwards, B. M., Burgess, R., and Thomas, E. (2019, September). *Neorecovery: A survivor led conceptualisation and critique* [Transcript]. Keynote presented at the 25th International Mental Health Nursing Research Conference, The Royal College of Nursing, London, UK. <u>https://recoveryinthebin.org/neorecovery-a-survivor-led-conceptualisation-and-critique-mhrn2019/</u>

⁸⁹ Chowdhary, N., & Warren, P. (2016, February 26). Better mental health in the global South: Key resources. *SciDev.Net*. https://www.scidev.net/global/features/mental-health-global-south-disoder/; Fleming, C. M., & Lim, R. F. (2015). Issues in the Assessment and Treatment of American Indian and Alaska Native Patients. In R. F. Lim & A. La Rue (Eds.), *Clinical Manual of Cultural Psychiatry* (2nd ed.). American Psychiatric Publishing.

The Indian Health Service, for instance, serves Indigenous people across the United States, but its materials are silent on the myriad atrocities that have been visited on Indigenous peoples, including the Trail of Tears, boarding schools, and other forms of physical and cultural genocide.⁹⁰ Instead, <u>the Indian Health Service's materials</u> treat psychosocial disability as something to be handled with medication and therapy only, disconnected from the grim realities that Indigenous people have faced—as well as from Indigenous understandings of neuroexpansive experiences.

- Affirm and validate people's struggle, and acknowledge the roles of trauma and systemic inequality. Racism, misogyny, anti-LGBTQ discrimination, ableism, classism, hostility toward immigrants, colonialism, poverty, hunger, homelessness, crushing debt, memories of rape and sexual assault, and domestic violence cannot disappear through the power of positive thinking. Instead, we must combat these systemic social problems with thoughtful policies and programs.
- Improve workplaces to make them accessible to autistic people. The stress of masking, camouflaging, or otherwise hiding one's autistic traits, can contribute to anxiety among autistic people. Some ways of making the workplace accessible include extra prompting to complete tasks, giving cues to remind an employee of what to do, implementing flexible remote work policies, offering office space with dim lighting, and providing extra breaks.

RESPECTING THE RIGHTS, DIGNITY, AND EXPERIENCES OF AUTISTIC PEOPLE OF COLOR

- Use specific and precise language to describe someone's mental health. Functioning language, such as "high-functioning" and "low-functioning," is harmful and may lead to denial of service, discrimination, and dehumanization.⁹¹
- Help guide autistic people through social situations without trying to make them identical to nonautistic people. Programs designed to stop people from stimming—using repetitive

⁹⁰ Walker, D. E. (2015, June 18). How the US Mental Health System Makes Natives Sick and Suicidal. *Indian Country Today*. Retrieved 3 September 2022, from <u>https://indiancountrytoday.com/archive/how-the-us-mental-health-system-makes-natives-sick-and-suicidal</u>

⁹¹ Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, 23(6), 1431–1441. <u>https://doi.org/10.1177/1362361318816053</u>

behavior to calm themselves down—can lead to symptoms of posttraumatic stress disorder.⁹²

- Create support programs that acknowledge the rights and dignity of autistic people of color. In 2021, the <u>World Health Organization</u> released a report that underscored the importance of rights-based approaches to mental health, using successful programs around the world as models.⁹³ The programs and strategies in the report listed can serve as examples to policymakers and advocates.
- Include autistic people of color when planning, delivering, and organizing mental health services. Without our input, practitioners will not know how to serve us best. This aligns with the disability justice principle of "leadership of the most impacted." Our direct experience will guide us in making recommendations that are based on our needs and circumstances. To include autistic people of color, organizations can appoint advisory boards, ensure that project leads are autistic people of color, conduct surveys and focus groups, and base recommendations on people's firsthand perspectives.
- Fund training for peer-support programs. Organizations like the <u>Wildflower Alliance</u>, Fireweed Collective, Project LETS, and <u>LUNA Community Care</u> have offered trainings to help people who are struggling with suicidal ideation, traumatic memories, and other forms of mental health distress.

⁹² Brewin, C. R., Rumball, F., & Happé, F. (2019). Neglected causes of post-traumatic stress disorder. *BMJ*, 365, l2372. https://doi.org/10.1136/bmj.l2372

⁹³ World Health Organization (2021). *Guidance on community mental health services: Promoting person-centred and rights-based approaches.* World Health Organization. <u>https://www.who.int/publications-detail-redirect/9789240025707</u>

Glossary

We sometimes use language that is drawn from psychiatric survivors, mad pride movements, and human rights organizations. Not everyone uses the same terms to describe their identities. There are many ways to describe people's identities and experiences. It reflects the reality that many people use–we use different terms about our own experiences, and even in our advocacy, we use different terms. Same goals, same principles, different language.

Affective disorders are psychosocial disabilities that involve distressing shifts in mood. Bipolar disorder and major depression are examples of affective disorder. For example, in some forms of bipolar disorder, people alternate between mania (an excitable state) and depression (an extremely low mood), with calmer periods in between. Affective disorders are also called *mood disorders*.

Altered states change people's perceptions of the world around them in striking ways. In some kinds of altered states, like intoxication or psychosis, someone may not be able to think clearly, or tell what's real and what isn't. Altered states can also make people more aware of the world around them, or can lead to spiritual experiences. Altered states can be caused organically (e.g., by psychosis or delirium), or by intoxication (e.g., alcohol, LSD, or marijuana). Trances, hypnosis, and meditation can also cause altered states. In this brief, we focus primarily on altered states that cause distress, like some forms of psychosis.

Applied behavioral analysis (ABA) is a practice that is designed to train people how to behave in socially desired ways. For example, autistic people who flap their hands to calm themselves or express joy are forced to stop, not because flapping their hands is harmful, but that nonautistic people don't typically express themselves this way. The methods practitioners use in ABA are abusive and dehumanizing. ABA is strongly condemned by human rights advocates.

The **biomedical model** focuses on biological causes of neurodivergence or psychosocial disability, such as brain chemicals, genetic markers, or diet. Treatment based on the biomedical model typically treats medication as the gold standard for alleviating mental distress. The biomedical model is often connected with neoliberal thinking. (See *Neoliberalism*).

Colonialism is a kind of *imperialism* in which people from a dominant country settle in another, often displacing the native population through segregation, genocide, or forced migration. The United States and Brazil, for example, were founded through colonialism.

A **crisis** (mental health crisis, psychiatric crisis) happens when someone feels they are in danger because of a mental health difficulty. For example, extreme depression that causes someone to have suicidal thoughts or attempt suicide is a crisis. Sometimes being in a

An **extreme state** is a kind of altered state that causes distress and may result in a crisis. Psychosis is an example of an extreme state.

Functioning labels, such as "high-functioning" and "low-functioning," are used to determine how well someone is able to live in the community. These labels are oversimplified and inaccurate, since people's skills can vary wildly. For example, someone may be able to work a 9-5 job, but they may not be able to clean their house or do their taxes on their own.

The **Global North** consists of highly industrialized, rich countries in North America, Europe, and East Asia, such as the United States, South Korea, Japan, and France. The term arose as a replacement for "First World," popular during the Cold War.

The Global South is made up of lower-income countries, especially former European colonies, in Africa, much of Asia, and Latin America, including Mexico, India, China, Yemen, Nigeria, Laos, and Colombia. Most countries are in the Global South. Global South is not identical to non-Western—Japan and South Korea are non-Western countries, but they are not in the Global South. Like "Global North," "Global South" came into use as a replacement for the Cold-War-era "Third World."

In **imperialism**, countries use their power to dominate others, especially to extract labor or resources. History is full of empires, including Ancient Rome, Great Britain, and China.

The **Mad Pride movement** is a radical movement led by people with psychosocial disabilities. Members of the movement embrace their identity, reject strictly medicalized definitions of mental health, and organize against coercive treatments.

Mental healthcare refers to a variety of services to support people with their mental health, including psychiatry, talk therapy, and peer support groups.

Mental health crisis: see Crisis.

Mental illness is the traditional term used to describe mental health conditions, particularly those caused by distress. The term is sometimes associated with stereotyping, discrimination, and prejudice, so many organizations have shifted toward terms like *psychosocial disabilities*.

Mood disorder is another term for *affective disorder*.

Neoliberalism is a set of policies and practices that emphasize individual responsibility over social causes. Neoliberal thinking leads governments to cut funding for social services, including mental health services, since they believe that people should be responsible for taking care of their own mental health. Neoliberalism also leads providers and researchers to choose treatment methods—which are often abusive and demeaning —that focus on the individual in isolation, like cognitive-behavioral therapy or applied behavioral analysis. **Neurodivergent** people think and perceive the world differently from *neurotypical* people. Neurodivergence includes autism, ADHD, OCD, intellectual disability, multiplicity/plurality, and major depression. The term neurodivergent was coined by Kassiane Asasumasu.

Neuroexpansive is another way to describe people often perceived as unwell, experiencing altered or extreme states, or with atypical cognition, emotions, and communication. This term rejects the assumption of any "normal" way of functioning, thinking, or feeling. This idea of "normal" functioning is rooted in a white and anti-Indigenous way of categorizing people's minds. The term neuroexpansive was coined by Ngozi Alston.

Neurotypical people's brains work in socially expected ways. Contrast with *neurodivergent* or *neuroexpansive*.

Peer support: People with psychosocial disabilities can offer each other help in groups, through organizations, or in one-to-one interactions. Types of peer support include peer-directed respite centers, support groups, online forums, social media groups, and more—when people with psychosocial disabilities build community with one another, it's peer support.

People of color is a catchall term used to refer to people of primarily non-European descent—e.g., West Africans, South Asians, or most Middle Easterners. Other people prefer the term **global majority**, referencing that white people are a numerical minority worldwide. Still others prefer the term **negatively racialized**. Negative racialization means that, under white supremacy, people are assigned racial categories, and some of these races are assigned negative values—e.g., Black people in the United States.

Practitioners refers to any professionals who support people with their mental health, including therapists, counsellors, doctors, social workers, and life coaches.

Psychiatric conditions: see psychosocial disabilities, mental illness, mental health conditions

Psychiatric disability is a term to describe disabling mental health conditions. It is often used alongside "mental ilness" and "psychosocial disability."

Psychiatric survivors are people who have experienced traumatic psychiatric treatment, including stays on locked psychiatric wards or harmful side effects from psychiatric medication.

Psychosis is a kind of *altered state* that causes hallucinations and delusions. When someone hallucinates, they see, feel, hear, or otherwise perceive things that others don't. Delusions are strongly held, fixed false beliefs that can't be reasoned away. Delusions are different from beliefs formed based on misinformation, or subjective spiritual or religious beliefs. Psychosis is common in people with bipolar disorder (especially during manic phases) and those with schizophrenia.

Psychosocial disabilities is a term used by international human rights organizations to describe conditions like bipolar disorder and clinical depression. The term emphasizes the role society plays in how we define and perceive our mental health.

Traditional healing is typically associated with non-Western cultures. Examples of traditional healing include Ayurveda, acupuncture, faith healing, shamanic journeying, and vision quests. Many of these practices are culturally specific and should not be adopted by people outside those cultures without being given explicit permission.

Western refers to countries dominated by Europeans or their descendants. Examples of Western countries include the United Kingdom, Spain, Germany, Sweden, Canada, and Australia. *Western* overlaps with *Global North*, though *Western* excludes higher-income countries elsewhere like South Korea, Israel, and Japan.





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