

[IACC's Co-occurring RFI](#) (January / February 2024)

Table of Contents

[Question 1](#)

[Question 2](#)

[Question 3](#)

[Question 4](#)

[Question 5](#)

[Question 6](#)

[Question 7](#)

Question 1

1. What are the most significant challenges caused by co-occurring physical health conditions in autistic people? (Examples of co-occurring physical health conditions: gastrointestinal disorders, sleep disturbances, epilepsy, sensory and motor challenges)

We thank the IACC for the opportunity to comment. We would like to note that given the importance of these issues, it is unfortunate that the submission format for this RFI significantly limits respondents' ability to provide thorough, meaningful comment. Please visit <https://bit.ly/48eGZzO> to view our comments in full, including citations.

Difficulties during pregnancy and birth are a common issue for autistic people. According to an NIH meta-analysis of 13 studies on pregnancy experiences in autistic people, we are more likely to experience "preterm birth, cesarean delivery, and pre-eclampsia".¹ Given what we know about Black maternal mortality,² we can extrapolate that Black autistic birthing people experience these issues at an even higher rate. More research is needed in this area. Forced birth is known to cause adverse health outcomes, especially for disabled people.³ Given abortion restrictions in the wake of *Dobbs v. Jackson* and the fact that many autistic people are on Medicaid/are, which does not cover abortions, these adverse outcomes are becoming a bigger problem for our community.

Police violence is an often-fatal threat to the physical health of Black autistic people and has been recognized as a public health issue.^{4, 5, 6, 7} Police violence is never the victim's fault and no amount of police training can solve this systemic issue on its own.⁸ To reduce this threat to our community, we must decrease police encounters and hold officers accountable for the harm they cause.

¹ McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood*, 3(1). <https://doi.org/10.1089/aut.2020.0046>

² Hoyert, D. (2023, March 16). Maternal Mortality Rates in the United States, 2021. *Www.cdc.gov*; Centers for Disease Control and Prevention. <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.htm>

³ Ravi, A. (2018, June 13). Limiting Abortion Access Contributes to Poor Maternal Health Outcomes. *Center for American Progress*. <https://www.americanprogress.org/article/limiting-abortion-access-contributes-poor-maternal-health-outcomes/>

⁴ APHA. (2018). Addressing Law Enforcement Violence as a Public Health Issue. *Apha.org*. <https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2019/01/29/law-enforcement-violence>

⁵ Atiba Goff, P. (2016). THE SCIENCE OF JUSTICE RACE, ARRESTS, AND POLICE USE OF FORCE. https://www.policingequity.org/images/pdfs-doc/CPE_SoJ_Race-Arrests-UoF_2016-07-08-1130.pdf

⁶ Robin, L., & McCoy, E. (2021, November 15). Policing Is Killing Black Disabled People. *Centering Intersectionality Is Critical to Reducing Harm*. *Urban Institute*.

<https://www.urban.org/urban-wire/policing-killing-black-disabled-people-centering-intersectionality-critical-reducing-harm>

⁷ Bradley, D., & Katz, S. (2020, June 9). Sandra Bland, Eric Garner, Freddie Gray: the toll of police violence on disabled Americans. *The Guardian*.

<https://www.theguardian.com/commentisfree/2020/jun/09/sandra-bland-eric-garner-freddie-gray-the-toll-of-police-violence-on-disabled-americans>

⁸ The Arc of the United States. (2022, September 16). The Inadequacy of Training: Police Interactions with I/DD and Mental Health Disabilities. *Www.youtube.com*. <https://www.youtube.com/watch?v=ljl4L03z9jA>

Question 2

2. What are the most significant challenges caused by co-occurring mental health conditions in autistic people? (Examples of mental health co-occurring conditions: depression, anxiety, attention-deficit hyperactivity disorder, aggressive or self-injurious behavior, suicidality)

Many mental health conditions are inequitably diagnosed among autistic people. One study found that Medicaid-eligible Black children were 5.1 times more likely than white counterparts to be diagnosed with adjustment disorders before being diagnosed with autism.⁹ Labels of oppositional defiant disorder or aggressive, dangerous, & self-injurious behavior (SIB) disproportionately affect autistic people of color, especially Black autistic people. Misdiagnoses delay access to therapeutic support, leading to mental and physical harm. SIB is separate from suicidality.

Studies from 2021¹⁰ & 2024¹¹ show disproportionate suicide attempts among autistic people. Suicidality is understood among those with lived experience as a “portal communicating to us what needs to change in society so that people want to live.”¹² Quality wrap-around services—not involuntary hospitalization—must be prioritized.¹³

The co-occurrence of gender dysphoria and autism is well-documented.¹⁴ Access to gender-affirming care is under threat,¹⁵ & it’s of critical concern to the autistic community. ASD screening should never be required to access gender-affirming care at any age because it perpetuates the discriminatory myth that autistic people are “too disabled” to know ourselves.¹⁶

Avoidant/restrictive food intake disorder (ARFID) is common among autistic people,¹⁷ & leads to nutritional deficiencies.¹⁸ There is a lack of interprofessional education, training, & knowledge about treating ARFID in autistic people.

⁹ Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2006). Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 37(9), 1795–1802. <https://doi.org/10.1007/s10803-006-0314-8>

¹⁰ South, M., Costa, A. P., & McMorris, C. (2021). Death by Suicide Among People With Autism: Beyond Zebrafish. *JAMA Network Open*, 4(1), e2034018. <https://doi.org/10.1001/jamanetworkopen.2020.34018>

¹¹ Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger’s syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, 1(2), 142–147. [https://doi.org/10.1016/s2215-0366\(14\)70248-2](https://doi.org/10.1016/s2215-0366(14)70248-2)

¹² Alaska, C. (2018, December). On Suicidality in Borderline Personality Disorder. Candice Alaska. <https://www.candicealaska.com/writing/Suicide-and-bpd>

¹³ Ward-Ciesielski, E. F., & Rizvi, S. L. (2020). The potential iatrogenic effects of psychiatric hospitalization for suicidal behavior: A critical review and recommendations for research. *Clinical Psychology: Science and Practice*, 28(1). <https://doi.org/10.1111/cpsp.12332>

¹⁴ Van Der Miesen, A. I. R., Hurley, H., & De Vries, A. L. C. (2016). Gender dysphoria and autism spectrum disorder: A narrative review. *International Review of Psychiatry*, 28(1), 70–80. <https://doi.org/10.3109/09540261.2015.1111199>

¹⁵ Trans Formations Project. (2024). National Bills. Trans Formations Project | Protect Trans Kids. <https://www.transformationsproject.org/national-bills>

¹⁶ ASAN. (2023, March 22). ASAN Condemns Restrictions on Gender-Affirming Care - Autistic Self Advocacy Network. <https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2023/03/asan-condemns-restrictions-on-gender-affirming-care/>

¹⁷ Bourne, L., Mandy, W., & Bryant-Waugh, R. (2022). Avoidant/restrictive food intake disorder and severe food selectivity in children and young people with autism: A scoping review. *Developmental Medicine & Child Neurology*, 64(6). <https://doi.org/10.1111/dmcn.15139>

¹⁸ Yule, S., Wanik, J., Holm, E. M., Bruder, M. B., Shanley, E., Sherman, C. Q., Fitterman, M., Lerner, J., Marcello, M., Parenchuck, N., Roman-White, C., & Ziff, M. (2021). Nutritional Deficiency Disease Secondary to ARFID Symptoms Associated with Autism and the Broad Autism Phenotype: A Qualitative Systematic Review of Case Reports and Case Series. *Journal of the Academy of Nutrition and Dietetics*, 121(3), 467–492. <https://doi.org/10.1016/j.jand.2020.10.017>

Question 3

3. What are the most significant challenges caused by other conditions that co-occur with autism, such as learning disabilities, developmental disabilities, intellectual disabilities, and communication disabilities?

Lack of support for communication creates significant challenges for people with learning, developmental, intellectual, and communication disabilities—not just the latter. All behavior is communication and behavior labeled as “challenging” is often an autistic person communicating or responding to an unmet need. ASAN has repeatedly emphasized a need for widely available, robust communication systems, including access to AAC devices.^{19, 20, 21} As noted by CommunicationFirst, only “some of this technology” is available “some of the time, in some states, for some people who can somehow navigate their byzantine, and often biased, processes and requirements.”²² We must do more to increase access to communication technology.

The lack of widely available plain language (PL) and Easy Read (ER) materials creates barriers for many autistic people with co-occurring disabilities. PL and ER materials give us more agency in decision-making, which has implications on guardianship determinations.²³ As ASAN stated in our comments on HHS’ proposed Section 504 changes, “guardianship is predicated on a ruling that an individual cannot make their own decisions or communicate them effectively. Providing disabled patients with health care materials in plain language and Easy Read would make these decisions substantially more accessible to those with a range of cognitive, developmental, intellectual, or neurological disabilities and thus reduce some of the impetus for guardianship applications.”²⁴

¹⁹ ASAN. (2019, April 18). Comments for April 17 IACC Meeting - Autistic Self Advocacy Network.

<https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2019/04/comments-for-april-17-iacc-meeting/>

²⁰ ASAN. (2021, November 22). ASAN Comments on the IACC Strategic Plan - Autistic Self Advocacy Network.

<https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2021/11/comments-on-the-iacc-strategic-plan/>

²¹ ASAN. (2023a, February 1). ASAN IACC Meeting Comments for January 18, 2023 - Autistic Self Advocacy Network.

<https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2023/02/asan-comments-for-january-18-2023/>

²² Communication FIRST. (2023, October 17). The FCC Needs to Address Digital Discrimination Against People Who Need AAC. CommunicationFIRST.

<https://communicationfirst.org/the-fcc-needs-to-address-digital-discrimination-against-people-who-need-aac/>

²³ ASAN. (2024, January 9). Comments for the January 24th IACC Meeting - Autistic Self Advocacy Network.

<https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2024/01/comments-for-the-january-24th-iacc-meeting/>

²⁴ ASAN. (2023c, November 14). ASAN Comments on HHS Proposed Updates to Section 504 - Autistic Self Advocacy Network. <https://autisticadvocacy.org/>.

<https://autisticadvocacy.org/2023/11/asan-comments-on-hhs-proposed-updates-to-section-504/>

Question 4

4. What additional research is needed to help address co-occurring conditions for autistic people?

Existing research, including reports from the Department of Defense’s TRICARE Autism Services Pilot, has pointed to the inefficacy of ABA: “43% [of ABA participants] demonstrated no improvement or increased intensity of symptoms over a two-year period”.²⁵ Other criticisms cite impacts like “consent violations and removal of autonomy, pathologizing unremarkable behavior, and interventions where the risks are greater than the benefits.”²⁶ However, we lack research that focuses on (a) additional harms of ABA to multiply marginalized autistic people, including those who are POC, Black and brown, nonspeaking, IDD, women, non-binary, trans, and LGBTQ+, from the Global South, people with mental health disabilities, people with co-occurring medical conditions, and people with higher support needs²⁷ and (b) additional benefits of occupational, sensory, and other therapies to those same groups.^{28, 29} Until research fully addresses the ways in which ABA specifically harms multiply-marginalized autistics, we cannot understand how to equitably formulate evidence-based ABA alternatives for these populations.

In general, autism research needs to be led by and developed with autistic people and address the needs of autistic children and adults across the lifespan. Autistic people need to be involved in all stages of research design and paid for our work. Research about our community must be made accessible to us by communicating key findings in plain language and Easy Read.

²⁵ US Department of Defense. (2021). The Department of Defense Comprehensive Autism Care Demonstration Annual Report. <https://health.mil/Reference-Center/Reports/2021/12/03/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-21>

²⁶ ASAN, ICDL, & WITH. (2021). For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions. <https://autisticadvocacy.org/wp-content/uploads/2021/12/ACWP-Ethics-of-Intervention.pdf>

²⁷ Ibid.

²⁸ Case-Smith, J., & Arbesman, M. (2008). Evidence-based review of interventions for autism used in or of relevance to occupational therapy. *American Journal of Occupational Therapy*, 62, 416–429.

²⁹ Schoen, S. A., Lane, S. J., Mailloux, Z., May-Benson, T., Parham, L. D., Smith Roley, S., & Schaaf, R. C. (2018). A Systematic Review of Ayres Sensory Integration Intervention for Children with Autism. *Autism Research*, 12(1). <https://doi.org/10.1002/aur.2046>

Question 5

5. What could be improved in autism services and supports to help address co-occurring conditions for autistic people? (Examples: Equitable access to and accessibility of services, insurance coverage, service systems issues, patient-provider interactions)

There is a dearth of accessible, affordable, & quality mental health (MH) care for autistic people with co-occurring MH conditions.³⁰ Providers lack the education & training,³¹ as well as competence & confidence,³² to serve autistic people of all ages, with or without intellectual disabilities. This service gap prevents autistic people from receiving necessary support.³³ Network inadequacy compounds the issue; “83.86% of all US counties lacked any diagnostic resources [for ASD].”³⁴ Provider quality & quantity urgently need expansion.

Punitive seclusion, restraints (mechanical or chemical), & other coercive measures create barriers to MH care for autistic people. These cruel anachronisms are used disproportionately on autistic people of color, particularly Black autistic men & boys. More retrospective research is needed on the long-term impacts of restrictive & coercive practices, like the incidence of PTSD.³⁵

Behaviorist interventions such as ABA should never be offered in lieu of or foreclose access to MH support. Behaviors termed “challenging or dangerous” are often natural responses to dehumanizing service systems or unsupported needs. These approaches prioritize outward conformity with neurotypical expectations over addressing underlying emotional distress. Effective modalities center patient agency. MH support includes, but isn't limited to, individual or group psychotherapy, peer support, social or affinity groups, & other types of therapy (physical, speech/language, sensorimotor).

³⁰ Lamar, Roxann R. (2020). *National Needs Assessment: Mental Health Services for People with Intellectual and Developmental Disabilities - National Summary of Results for States*.

<https://mhddcenter.org/wp-content/uploads/2020/04/MHDD-National-Needs-Assessment-2020.pdf>.

³¹ Lipinski, S., Boegl, K., Blanke, E. S., Suenkel, U., & Dziobek, I. (2021). A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum. *Autism*, 26(6), 136236132110579. <https://doi.org/10.1177/13623613211057973>

³² Barksdale, T. (2012). DigitalCommons@PCOM Clinician Factors in Psychotherapy Disparities for People With Intellectual Disabilities and Co- Occurring Mental Illness.

https://digitalcommons.pcom.edu/cgi/viewcontent.cgi?article=1226&context=psychology_dissertations

³³ Chiri, G., & Warfield, M. E. (2011). Unmet Need and Problems Accessing Core Health Care Services for Children with Autism Spectrum Disorder. *Maternal and Child Health Journal*, 16(5), 1081–1091.

<https://doi.org/10.1007/s10995-011-0833-6>

³⁴ Ning, M., Daniels, J., Schwartz, J., Dunlap, K., Washington, P., Kalantarian, H., Du, M., & Wall, D. P. (2019). Identification and Quantification of Gaps in Access to Autism Resources in the United States: An Infodemiological Study. *Journal of Medical Internet Research*, 21(7), e13094. <https://doi.org/10.2196/13094>

³⁵ Kupferstein, H. (2018), "Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis", *Advances in Autism*, Vol. 4 No. 1, pp. 19-29. <https://doi.org/10.1108/AIA-08-2017-0016>

Question 6

6. What lasting impact has COVID-19 infection and illness had on co-occurring physical and/or mental health conditions for autistic people?

Long COVID is itself a co-occurring health condition. Autistic people have been found to have significant sequelae after infection.³⁶ More research on autistic post-COVID experiences is needed, especially for Black and Hispanic people who “are more likely to report symptoms of ‘Long COVID’ than their White peers” though “White people are more likely to have a documented case of the illness”.³⁷ Because of the heightened risk to our health,³⁸ many disabled people have continued to take COVID precautions while many nondisabled people have stopped. Many autistic people are dismissed as “overly anxious” about COVID-19 when we insist on PPE and other precautions. In some cases, disabled people have delayed medical care because their providers refuse to wear PPE at appointments. We would like to see acknowledgment of PPE in medical settings as a reasonable accommodation under the ADA.³⁹

As public awareness and reporting on COVID-19 has decreased throughout the pandemic, vital COVID-19 resources have disappeared. ASAN had to end its COVID-19 case tracker due to lack of data.⁴⁰ Project N95, which donated vetted PPE to those in need, had to shut down due to decreased public support for masking and a resulting lack of donations.⁴¹ The loss of crucial resources as COVID continues to circulate and take lives needs to be addressed. COVID is an airborne virus, and proven methods of transmission reduction such as air quality monitoring, HEPA filters,⁴² and respirators⁴³ should be broadly used.

³⁶ Jyonouchi, H., Geng, L., Rossignol, D. A., & Frye, R. E. (2022). Long COVID Syndrome Presenting as Neuropsychiatric Exacerbations in Autism Spectrum Disorder: Insights for Treatment. *Journal of Personalized Medicine*, 12(11), 1815. <https://doi.org/10.3390/jpm12111815>

³⁷ Heath, S. (2023, February 17). NIH Uncovers Racial Disparities in Long COVID Symptoms, Diagnosis Rates. *Patient Engagement HIT*; Xtelligent Healthcare Media.

<https://patientengagementhit.com/news/nih-uncovers-racial-disparities-in-long-covid-symptoms-diagnosis-rates>

³⁸ IntellectAbility. (2022, June 20). Long-haul COVID in People with IDD. IntellectAbility.

<https://replacingrisk.com/download/long-haul-covid-in-people-with-idd/>

³⁹ People's CDC. (2023, May 9). ADA Rights Workshop. People's CDC.

<https://peoplescdc.org/2023/05/09/ada-rights-workshop/>

⁴⁰ ASAN. (2023a, January 30). Lack of data forces ASAN to end COVID-19 Case Tracker - Autistic Self Advocacy Network. <https://autisticadvocacy.org/>

<https://autisticadvocacy.org/2023/01/lack-of-data-forces-asan-to-end-covid-19-case-tracker/>

⁴¹ Mather, V. (2023, December 5). Two N95 Companies Shut Down, as an Era Ends. *The New York Times*.

<https://www.nytimes.com/2023/12/05/business/covid-mask-n95.html>

⁴² Clarke, R. D., Garba, N. A., Barbieri, M. A., Acuna, L., Baum, M., Rodriguez, M. S., Frias, H., Saldarriaga, P., Stefano, T., Mathee, K., Narasimhan, G., & R Brown, D. (2023). Detection of SARS-CoV-2 in high-efficiency particulate air (HEPA) filters of low-cost air purifiers in community-based organizations. *Environmental Monitoring and Assessment*, 195(11), 1320. <https://doi.org/10.1007/s10661-023-11950-y>

⁴³ ACGIH. (n.d.). COVID-19 Fact Sheet: Workers Need Respirators. ACGIH.

<https://www.acgih.org/covid-19-fact-sheet-worker-resp/>

Question 7

7. What lasting positive or negative impacts have societal changes due to the COVID-19 pandemic had on physical or mental health for autistic people? (Examples of societal changes: disruptions in services, increased remote work and school, increased use of telehealth, reduced in-person social interactions and obligations)

The ongoing COVID-19 pandemic -as well as policies implemented to mitigate it- have had enormous impacts on autistic people for both good and ill.⁴⁴ For example, the continuous coverage provisions authorized by the Families First Coronavirus Response Act enabled autistic people to maintain access to health care and services, and its expiration caused many autistic people to lose coverage.⁴⁵ Provisions of the HCBS Settings Rule relating to community integration were delayed,⁴⁶ which further heightened social isolation for those in congregate settings, while service disruptions⁴⁷ put autistic people at further risk of institutionalization or reinstitutionalization.⁴⁸

The provider shortage—while exacerbated by the pandemic—predates COVID-19 and must be addressed as a longstanding and systemic issue. In order for autistic people to receive higher quality care, direct support providers must be paid a liveable wage, receive adequate training, & be free from workplace racism, sexism, & xenophobia.

Increased use of and support for telehealth has expanded access to mental health providers and specialists, including for those who need specialist care that is not readily available locally. Efforts to preserve telehealth availability should ensure that they are and remain accessible for autistic individuals, particularly those with intellectual or communication disabilities.

⁴⁴ People's CDC. (2024, February 5). People's CDC COVID-19 Weather Report. People's CDC. <https://peoplescdc.org/2024/02/05/peoples-cdc-covid-19-weather-report-67/>

⁴⁵ Kaiser Family Foundation. (2023, June 20). Medicaid Enrollment and Unwinding Tracker. KFF. <https://www.kff.org/medicaid/issue-brief/medicaid-enrollment-and-unwinding-tracker/>

⁴⁶ Fracht, A., Mairose, D., & Phillips, A. (2022, November 7). COVID-19 Experiences of Persons with Intellectual Disabilities. HPOD. <https://hpod.law.harvard.edu/news/entry/covid-experiences-group-homes>

⁴⁷ Wong, A. (2024, January 17). COVID Isn't Going Anywhere. Masking Up Could Save My Life. Teen Vogue. <https://www.teenvogue.com/story/covid-isnt-going-anywhere-masking-up-could-save-my-life>

⁴⁸ ASAN. (2023d, March 23). ASAN IACC Meeting Comments for April 4, 2023 - Autistic Self Advocacy Network. <https://autisticadvocacy.org/>. <https://autisticadvocacy.org/2023/03/asan-iacc-meeting-comments-for-april-4-2023/>