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

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

Public Comments

January 18, 2023

Contents

Oral Comments

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

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

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

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

- **The mental health of autistic people of color, autistic immigrants, and autistic refugees.** Although some studies exist on the prevalence of psychiatric disabilities among autistic people, very few examine the relationship of race, autism, and mental health together. Studies have shown that autistic people, regardless of race, are already more likely to experience anxiety, depression, suicidality, bipolar disorder, obsessive-compulsive patterns, and psychosis.[1] We hypothesize that systemic racism and racialized anti-immigrant discrimination contribute to increased rates and severity of psychological distress among autistic people of color and autistic immigrants and refugees, but we need more empirical research to test this hypothesis and support appropriate funding allocations in the future.

- **The involvement of autistic people in autism research.** For years, autism research has been dominated by the needs, priorities, and experiences of non-autistic people. This means that our voices are often silenced and marginalized. For research to reflect our true needs, priorities, and concerns, it must include us from the start. We encourage IAAC to prioritize research models such as community-based participatory research and community-based participatory action research, as exemplified by research collaboratives like the Patient-Centered Outcomes Research

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

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

- **The use of anti-ableist language and approaches.** We support increased funding for high-quality research that is responsive to autistic people's needs, improves short- and long-term outcomes for autistic people, and reflects the priorities of autistic people who consistently receive the least support, recognition, and access. This includes those who face multiple forms of marginalization, autistic people who are also primary or secondary caregivers for other autistic and disabled people, autistic parents of autistic children, and autistic people with multiple chronic health conditions. To accomplish these objectives, IACC should encourage researchers to use respectful, anti-ableist language and approaches in their methods and published work. Anti-ableist approaches to research enable researchers to address systemic issues that affect autistic people's health, outcomes, and experiences of our disabilities. Anti-ableist values also invite researchers to consider the ultimate aims and consequential impact of their projects in relation to improving social and material conditions for autistic people.

- **The effects of gender bias against women (both transgender and cisgender women), people with feminine gender expressions and presentations, and any people assigned female at birth with neurodevelopmental disabilities and co-occurring conditions.** For example, endocrine conditions are often connected to the worsening of mood disorder symptoms, with or without psychotic features.[2] Chronic inflammation, a feature common in autoimmune disorders, is more likely to occur in women, people assigned female at birth, and autistic people—and that chronic inflammation can result in autoimmune disorders such as diabetes and cardiac disease.[3] Additionally, all women and gender non-conforming people face significant, well-documented disparities in access to appropriate identification or diagnosis and effective supports.

- **The effects of school disciplinary policies and the school-to-prison pipeline on autistic students of color.** Students with disabilities are disproportionately likely to be expelled or suspended from schools that use zero-tolerance disciplinary policies, as are students of color.[4] Most research focuses on students with disabilities as a

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

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

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

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

- **Healthcare experiences of autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees**. These experiences can include interactions with medical professionals and other clinicians, hospitalizations, accessibility in hospitals and clinics, communication barriers, denial of care, lack of parity in insurance coverage, and affordability of healthcare services, among others. Racial disparities negatively affecting Black, Native/Indigenous, Latine, and Asian communities in healthcare service provision and health outcomes are well documented.[5] Additionally, as the Committee may already know, researchers from the University of Cambridge published findings only last year that autistic people were more likely to identify as asexual, bisexual, and "other [LGBTQ+ identities]."[6] Health disparities negatively affecting LGBTQ+ people are also well documented.[7] For that reason, funding research on development and use of guidelines and standards (for example, on cultural competency and communication access) for providing healthcare to autistic people would be beneficial.

- **The rate and effects of homelessness and unstable housing on autistic people.** Some research has shown that autistic people are more likely to be homeless than non-autistic people, but there are relatively few studies.[8] Most of this research has taken place in the United Kingdom, whose sociocultural context is different from that of the United States. Researchers should pay particular attention to the prevalence of

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

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

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

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

Stacey M. Blecher

After listening to Dr. Daniels speak at OCALICONLINE I decided to write a public comment. I am a Board Certified Art therapist in the state of Ohio. I have been working with Autistic children age 5-22 for the last decade. I also am a wife of a husband who has been diagnosed with high functioning Autism. Autism is all around me. As an art therapist I find that it's truly a shame that there are not more services for higher functioning adults that are covered by insurance. Typical mental health and "talking" doesn't work for many autistics. However, as an art therapist I have found that this is a service that benefits so many autistics. It provides them the ability to express their thoughts feelings with out the use of words. My husband will say can we just text or can we just not talk. His level of overwhelm at the end of the day he just can't find the words. As a country I think there is way more we could be doing for the autistic population to provide services not just in an area of heavily concentrated populations but across rural areas too. If the expressive therapists could have greater access to support this amazing population federally funded or federally meeting medical necessity. I think our society would be great. Often times in the community people are seeking supports and are on a wait list for 1 year or longer. This would provide accessability to providing a much needed service to those in need.

Thank you for your time.

Areva Martin, Esq., Special Needs Network

I would like to thank the members of the IACC for allowing me to offer testimony today. I am speaking to you as the Founder and President of Special Needs Network, as a civil rights attorney, and as the mother to a child with an autism diagnosis.

You are aware that federally qualified health centers are entitled to federal grant money and enhanced Medicaid payments for certain licensed providers. These supplemental payments make it financially feasible for clinics to operate in poor and historically underserved neighborhoods. But a critical community of providers is left out of the current legislative scheme that enables those supplemental payments—the behavioral health specialists who provide critical services and intervention for those with autism and other developmental disabilities.

You are aware that federally qualified health centers are entitled to federal grant money and enhanced Medicaid payments for certain licensed providers. These supplemental payments make it financially feasible for clinics to operate in poor and historically underserved neighborhoods. But a critical community of providers is left out of the current legislative scheme that enables those supplemental payments—the behavioral health specialists who provide critical services and intervention for those with autism and other developmental disabilities.

Although states don't have a licensing process for behavior analysts, BCBAs are highly educated in their field; most have master’s degrees and many have PhDs. Their education and expertise allows them to conduct assessments of children with behavioral health issues, write treatment plans, provide direct intervention services, and even supervise other clinicians providing direct intervention services. However, under current Medicaid provisions, these experts are not considered “qualified” when delivering services to someone who has Medicaid insurance.

This arrangement puts providers like Social Needs Network at an extreme disadvantage even as we deliver much needed behavioral health treatment to the most vulnerable patients in the communities we serve. This reality is detrimental to our capacity to pay our clinicians, to expand our services, or simply operate at a level that is sustainable. The reality is preventing organizations from serving these vulnerable populations. As we face a crisis point in being able to deliver services, Special Needs Network is requesting your help in communicating to the Office of Health and Human Services of the dire need to expand the definition of providers under Medicaid who are eligible to receive enhanced payment.

This change would make available a larger pool of providers to deliver behavioral health treatment to our nation's most vulnerable patients—those at the intersection of disability, racial inequities, and poverty. Today, 1 in 44 children are diagnosed with autism. That is a 244% increase over the year 2000. The data is clear that earlier intervention brings better outcomes and affords people greater opportunities to lead productive and fulfilling lives. Earlier intervention also benefits society as a whole: National Audit Office research indicates that supporting more people with high-functioning autism and Asperger syndrome quickly becomes cost neutral, and can potentially lead to long-term savings from higher tax incomes and reduced benefit payments as people are supported into employment. Such intervention also reduces mental health and criminal justice costs as people are supported before they reach a point of crisis.

There is precedent for the advocacy we are requesting. The Improving Access to Mental Health Act of 2021 proposes amending the current law that prevents clinicians from billing Medicaid for behavioral health care. If passed, the bill would allow clinicians to bill for 75% of a psychologist's rate and would also increase the reimbursement rate for clinical social workers from 75% to 85% of the physician fee. If this bill is reintroduced in the new Congress, we see an opportunity to support the expansion or an amendment that would increase the reimbursement rate for those certified behavior analysts who provide behavioral health treatment.

This is about advancing equity and racial justice. The current scheme creates a dual system where the wealthy have access to more providers and services, while low income and poor people—particularly people of color—are receiving diagnosis, assessment, and intervention services two years later than their peers. Increasing provider payment rates for Medicaid will help improve provider participation and expand access to care for those who have, for too long, been left behind by an unjust system

Joseph P. Joyce, M.B.A., Autism Society of America

Written Testimony of Joe Joyce

On behalf of the Autism Society of America

For the Autism Interagency Coordinating Committee

January 18, 2023

Thank you, Dr. Gordon and the rest of the Interagency Autism Coordinating Committee (IACC) for allowing me to provide written testimony and brief comments this afternoon. I am providing this testimony on behalf of the Autism Society of America; however, I will also share my personal story as a father of two adult sons with developmental disabilities.

The Autism Society of America is the largest and oldest grassroots organization established in 1965 by parents caring for what was then, an unusual disability called "Autism." Not much was known about the disability back then. What these parents shared was the desire to help their children with significant disabilities live as fully as possible. They shared information and advocated for educational and other services to help them be healthy, able to live at home, and be accepted in the community. The Autism Society continues this mission.

I am the father of two individuals with significant functional limitations: David, age 24, has Autism, and Matt, 26, has Down Syndrome; both have intellectual and developmental disabilities. Developmental disabilities are defined in law (the DD Act) as physical or mental impairments that begin before age 22, are likely to continue indefinitely, and result in substantial functional limitations in at least three major areas of self-care. In spite of these limitations, both of our young men are loved and valued members of our family and community. David and Matt are handsome, loving, thoughtful, and caring individuals with so much to contribute to our family. We have no regrets regarding the decision to raise them at home. My wife, Elise, and I have been caring for them and our beloved daughter, Tara, their whole lives.

Elise and I were finally able to transition David to a home that we bought for him. However, it was a massive struggle to find direct support professionals and a licensed agency to operate the home. Many agencies declined due to inadequate provider rates to serve high-risk residents. We are fortunate to have some resources for this planning but millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care, food, and housing assistance. Matt continues to live with us as we plan his transition to living more independently but we worry about being able to find a home and professionals that will be able to help him. We know that David and Matt will not be able to care for themselves without significant support. We worry about what will happen to them when we are no longer here to take care of them and coordinate and oversee their services.

The Home and Community-based Medicaid waiver is the program that most individuals and families depend on to get the services they need to keep family members at home, get habilitation, behavioral health, and supported employment. However, the only service that states are required to cover is home health. Most other services are optional. States are also permitted to limit the number of people eligible for waivers resulting in waiting lists, that in some states are many years long. In addition, states vary in the way they screen and collect data on waiting lists and they vary in the pay rates for direct support professionals.

Waiting list totals across all disabilities for states that self-reported in 2020 were 665,000 individuals. The actual HCBS waiting list number is estimated to be 820,000 individuals as CA, CT, NC, NH, and NM either did not report totals since 2018 or did not submit a complete report of all waiver programs and disabilities. Strikingly, the number of individuals with mental illness waiting for HCBS services for all states was 1,844, while 464,398 individuals (or 251 times the number of their mental health counterparts) with intellectual and developmental disabilities were on a waiting list. Even more troubling, individuals wait on average 39 months to secure services, with reports of some waiting 15 years. There is an urgent need to remedy this crisis as the prevalence of Autism is expected to increase by 15 percent over the next ten years. Pennsylvania reports that approximately 17,000 are waiting for services and is one of only 5 states (FL, IL, IN, ND, PA) that does not provide individuals state plan services while on the waiting list.

New data from ANCOR finds that a significant shortage of direct support professionals has reached catastrophic levels. The longstanding workforce crisis, exacerbated by the COVID-19 pandemic, has led to closures of critically needed services and a denial of access to community-based support. Vacancy rates for full-time direct support positions increased from 8.5% in 2019 to 12.3% in 2020—a roughly 45% increase.

My family experienced this shortage first-hand. During the height of the pandemic, David’s day habilitation services (Hope Springs) was completely closed for 12 months, putting significant strain on working parents. Many of the direct service providers sought employment elsewhere, resulting in a significant shortage of staff. We are so fortunate that Hope Springs survived the crisis, thanks, in part to federal government funding packages. However, Due to the staff credentials required for high risk behaviors, David has not yet been able to return to the day program at pre-pandemic levels.

Federal funding for the Covid public health emergency is coming to an end putting the community-based service system in jeopardy of complete collapse. The direct support workforce crisis is due, in part to an inability of providers to offer wages that are competitive with those of hourly-wage industries, such as fast food, retail, and convenience stores. We must find a way to pay trained professionals to help care for our loved ones.

In all the years I have been involved in the Autism Society, I have never been more worried about the state of our nation’s service system for people with Autism and other developmental disabilities. We receive way too many calls to our hotline related to individuals and families suffering without services. The Administration and Congress must find the political will to help states provide these services.

Following are just some of the recommendations the Autism Society has for the Administration and Congress to address these issues:

- Reverse the bias in Medicaid, so that home and community-based services and supports are mandated within the state plan.
- Extend the temporary increased funding for the federal Medicaid match (FMAP) authorized under the American Rescue Plan Act.
- Support policies included in the Better Care Better Jobs Act (S. 2210/H.R. 4131 in the 117th Congress) that supports direct support professionals.
- Establish a standard occupational classification (SOC) for Direct Support Professionals. SOCs are used to help all levels of government identify employment trends and design policies, including states' approaches to rate-setting in their Medicaid programs
- Create a national long-term care system outside of Medicaid.
- Provide funding for new demonstrations for states to test community-supported living arrangements to help provide housing options in the community for people with developmental disabilities and those who are aging.
- Mandate the state Medicaid buy-in program so that people can work and still get health care (now an option for states through Social Security Section 1619(b)).
- Implement the many good policy recommendations provided by the RAISE Family Caregiver Councils to support families caring for individuals with Autism.

While we understand that IACC does not have jurisdiction over Congress, we hope that you will use the influence of this body to do what you can within the agencies around this table to make an impact and to make recommendations to Congress to improve services for those with Autism.

The Autism Society has numerous professionals, family members, and individuals on the autism spectrum with expertise and willingness to help. Please contact me or Kim Musheno, VP Public Policy at our national office at 301-657-0881 for more public policy recommendations to address the issues addressed above.

Sources:

Alice Burns, Molly O'Malley Watts, and Meghana Ammula
A Look at Waiting lists for Home and Community-Based Services from 2016 to 2021 (Nov 28, 2022)

National Council on Disability report: Strengthening the HCBS Ecosystem (Dec. 2022)

Kaiser Family Foundation: Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility (2021)

ANCOR and UCP, The Case for Inclusion 2022 Blazing Trails to Sustainability for Community Disability Services (2022)

ANCOR, The State of America’s Direct Support Workforce Crisis 2022

Thomas Frazier, Ph.D., Autism Speaks

I’m Dr. Thomas Frazier, Professor, Department of Psychology, John Carroll University and Autism Speaks board member. In 2019 the IACC held a workshop addressing the mental health needs of people on the autism spectrum. Participants in the workshop discussed co-occurring mental health issues that affect many people on the autism spectrum, including anxiety, depression, suicide, self-injurious and other severe and distressing behaviors. A recent Washington Post story highlighted the plight of an autistic teen who waited months for a psychiatric bed to become available in a facility that could provide appropriate care for him. The teen seized and died days after being admitted to a psychiatric facility.

The workshop, the newspaper story, personal accounts, in separate ways speak to the distance between the mental health services the community needs and the services the community receives. But there is an opportunity, provided by the recently enacted Consolidated Appropriations Act, 2023, to make up ground for autistic individuals with co-occurring mental health conditions with the most significant unmet health needs. The Omnibus agreement directs NIMH to deliver with the fiscal year 2024 Congressional Justification a “professional judgement” budget estimating the additional funding needed to support opportunities broadly to accelerate research on serious mental illness (SMI). The agreement goes on to specify that the budget should include efforts to expand existing scientific programs focused on improving early identification, accurate diagnosis, biomarker assessment, intervention development, and implementation of effective services, among individuals in the early stages of SMI.

The Omnibus agreement also urges the NIH to provide an update on its investment across the priority areas outlines in the IACC Strategic Plan in the fiscal year 2024 Congressional justification. This language, coupled with the new professional judgement budget for SMI, offers an unprecedented opportunity for the IACC to engage and articulate a path towards addressing some of the unmet mental health needs of our community, particularly for those with the most significant health care needs. The IACC should seize the opportunity. Consistent with the language of the Omnibus, the IACC should identify time-limited, goal-driven investments that the funding identified in the professional judgment should address.

Countless individuals and families have waited for an answer to the lack of accessible, quality mental health care. The time to address this real and growing concern is now.

Written Comments

Research and Service Needs, Resources, and Policy Implications

Trixie Morales-Miller

Please stop researching a cure for autism, instead do research on how autism manifests in people of color, women, and queer people.

Andrea Davis, Ph.D.

As president of the DIR/Floortime Coalition of California, I urge the committee to prioritize research of respectful approaches to supporting autistics in order to provide a choice of approaches. Families and autistic adults do not have access to evidence-based treatment since the definition of evidence-based care includes the medical provider selecting the appropriate approach for an individual. Due to insurance funding ABA-only in most states, there is no provider choice or selection for an individual possible. Research meta-analyses show limited or negative effects of ABA (Department of Defense Tri-Care study) and meaningful social communication outcomes of developmental, relationship-based (DRBI) therapies (Sandbank, M. et al Project AIM study). The committee should add a goal to support outcome research in developmental therapies. Developmental approaches to support and therapy are based in Developmental Psychology research and principles, a desperately needed alternative to behavioral treatment or ABA, based in Behavioral Psychology and behaviorism. Developmental therapies such as DIR/Floortime approaches to speech therapy, sensory-integration OT, mental health, home support, community support, and education aim to tailor the interactions of the parents, caregivers, and others around an autistic individual to that person's individual differences or unique neuropsychological profile so the individual may function in ways they wish to function and meet their own goals for happiness and thriving however they wish. Inequity reigns here in that wealthy families self-fund developmental therapies and their autistic loved ones benefit greatly; autistics of limited means cannot afford to self-fund developmental therapies. Further research supporting respectful developmental intervention or supports will help to change ABA-only insurance policies, state policies, and federal policies which so far have hampered equitable treatment access to developmental therapies. IACC can change this unfair situation by committing to demonstration research for developmental therapies.

Joshua Feder

Outcome studies are critical for measurement of the efficacy of efforts to support autistic individuals to reach meaningful functional goals. There are very few such studies, and when we hear the concerns from autistic people themselves, we hear calls for including them in the process of research adn program design, and a call for recognizing neurodiversity and the need for support and accommodations rather than defining them as disordered as if their autism is an entity to be excised or healed. Outcome studies can look at functional outcomes including process variables such as better regulate, meaningful connection to others, and developmentally effective social problem solving and academic function, and distal outcome variables such as employability in satisfying work, living in settings that meet needs for shelter, sustenance, and safety, and connection to community and to others that may range from a tolerable safety net to stable and sustained interpersonal relationships. This kind of research requires

careful consideration and a commitment to follow up on the order of the Nurse's Health Study. While such an enterprise might costly, the high costs of autism treatment natioanlly in the US, estimated at $236 to $261 billion annually (1), coupled with disappointing outcomes in the few existing large scale studies (2) and the inability to demonstrate efficacyy for the dominant approach to autism (3) demand better research on the real efficacy of outcomes.
(1) https://www.autismspeaks.org/autism-statistics-asd
(2) https://therapistndc.org/wp-content/uploads/2020/08/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-2020.pdf
(3) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8783568/

Diane Cullinane

I would like to see funding on how many people with autism respond to gluten free diet. This would include those who have celiac disease, and others who do not have celiac but still respond to the diet. I hear of many families who try this or other diets without good evidence of effectiveness.

Kaitlyn Ballenger

I would like to see research on why so many autistic people suffer from tinnitus and EDS and would like to also see research on effective treatment for those co-morbidities.

Lisa Wanionek

I suggest research on ways to individualize school and work schedules based on needs to feel safe, supported and successful. For example, some may thrive with shorter work schedules, flexible schedules, and being able to have control over their environment either from being able to do work remotely or have areas to stim or decompress and regulate emotionally.

I also think that classrooms and work spaces could be more sensory friendly and offer accommodations regardless of Autism or disability disclosure. Some folks may not know they are on the spectrum yet, some may not feel comfortable disclosing that information.

Research on shorter work days and shorter work weeks (with the same level of pay....e.g. no pay reductions for reduced hours)for adults on the spectrum to minimize levels of autistic burnout. There are other countries who have been experimenting with 4-day work weeks without increasing hours AND maintaining the same salaries as when they were working 5 day work weeks.Traditional work set ups are not a good fit for folks on the spectrum...who knows, maybe everyone would benefit from these types of changes.

Research on Autistic Burnout: how to identify it, recover from it, and prevent it. How school, work and society in general can shift in positive ways to support folks on the spectrum and other disabilities to thrive in all areas of their lives.

How to create sensory friendly spaces in the community: movie theaters, grocery stores, other stores, libraries, etc.

Marrok Sedgwick

Please fund research utilizing cognitive psychology and learning sciences (neither of which, by definition, consider behaviorist psychology empirically supported) perspectives to try to understand how autistic people of all support needs learn, and therefore how to create inclusive educational settings that support their learning.

Tifiny Spiva

We don't need any more research into how to make our behaviors fit into neurotypical standards or how to cure or prevent people like us from existing. Please put more funding into helping us get the health care we need, and to providing actually autistic researchers the funds they need to study what they want to discover about us.

Melissa Woronoff

Current research on autism disproportionately focuses on behavioral therapies, biomedical studies, and causation and prevention. According to the neurodiversity model, Autism is a neurotype not an illness. As a psychologist and a mother to two incredible and capable autistic children, I strongly believe that further research must focus on Autism as a minority neurotype that deserves a voice. The goal of research should be to better understand how to make the world a more comfortable place for this minority group and how to help allistic individuals better understand the autistic community. Research must be driven by the autistic community with autistic scientists, psychologists, and others leading the way. Money spent on preventing autism or getting rid of autism is waisted. Autistic individuals are valuable innovators that our society needs.

Natalie Dowd

Please consider whether new research is benefitting individuals with autism. A movement to cure or end autism is not helpful. Since not all autistic people have seizures or self-harm (as examples) it is not fair to use these reasons to eliminate an entire way of thinking that is a part of many peoples' identity. Research should help the communities or people being studied. Pediatric research should involve input from adults with autism, especially those who themselves participated in research or had interventions as children.

JL Angell

Right now, research funding on autism still disproportionately focuses on behavioral therapies, biomedical studies, and causation and “prevention.” Research priorities should reflect what the autistic community needs, including what actually facilitates independent living and workplace accommodations for successful careers.

Jasmine Etienne

I have seen research that focuses on the causes and prevention of ASD; I would rather see research that asks autistic people, specifically, what defines our experiences. I know that typically, psychology takes a behavioral approach rather than a metacognitive approach, but I worry that a failure to take autistic opinions into account may mean that the diagnostic criteria and identification of autistic individuals may be limited.
I would also like to see research that focuses on co-morbidities and overlapping identities and conditions, including why things such as POTS, Ehlers-Danlos syndrome, and gastrointestinal upset are so common in autistic people.
I would like to know if ASD is actually more common in white men, or if the diagnostic criteria and potential provider bias is to blame for women, queer people, and people of color not getting diagnosed until they are much older. What is the overlap between children identified as gifted in school and those who are autistic? Why do so many of us only get noticed as gifted, and have our struggles dismissed?
A lot of autistic people do not agree with the usage of Applied Behavioral Analysis therapies. Is there a way that research can be done where their experiences are heard, and adaptations or changes can be made to the way we treat autism?
How many autistic people need specialized therapies, and how many of us would be fine with standard talk therapy, accommodations, fidget tools, and public acceptance/education?

In closing, I would like to wonder aloud, so to speak, as to whether we can find a middle ground between research needs and findings, and the expressed needs of autistic people. ABA therapy, for example, is best from the standpoint of making us seem more "normal", but it tampers with our abilities to self-regulate and express ourselves in the ways that are most natural to us. Is there a middle ground, to calm behaviors that are harmful while allowing odd but ultimately harmless behaviors? Textbooks call them "nonfunctional behaviors", but they allow me to regulate the intensity and variety of sensory input in my day-to-day life.

Lisa Graf

Please research the increase of families opting out of ABA for their autistic child(largely because the Autistic Community is against ABA). Are there schools districts that are offering supports that are within a framework of the neurodiversity movement instead? Please research this topic as this is the direction that school districts are moving towards even if this shift is moving slowly. Please support and not hinder this movement to human rights for autistic individuals.

Paola Simi

As an autistic person, I believe autism research should move away from trying to “fix” autistic people and instead focus on acceptance, and focus on research that actually improve the lives of autistic people.

I think the IACC should tell the government to pay for autism research about other health problems that autistic people commonly experience. For example, stomach problems and trouble sleeping.

Additionally, autism research should focus on ways to make school and work more accessible to autistic people; how we can accommodate different kinds of communication, and increase effectiveness and accessibility of support services. Again - more emphasis on improving the lives of autistic people, not forcing people to change to fit allistic standards of "normal."

Autism research should focus on both children and adults. It is important that research on autism includes people of color, women and non-binary people, and people with intellectual disabilities; their voices deserve more recognition and representation. Above all, autism research should be listening to autistic voices. Autism research that only focuses on a small subset of the community leaves numerous autistic people without adequate support and understanding.

Thank you for reading my comment.

Eliza May

As an autistic adult I heavily oppose research into genetic factors of autism, especially where they may be misused for abortion screening. This is a precursor to eugenics.

Tosha Brothers

I am starting off this comment assuming that the IACC will consider how wide the spectrum of autism extends outward, and how we are all different in our needs and capability. All opinions expressed are my own, and I will step into the new year strong with the hope that autistic people can live as who they are, regardless of prejudice, and retain their natural freedom of expression, whatever form that may take.

I am increasingly concerned by the discourse around autistic eating habits as it currently manifests. Especially regarding the research still in its infancy known as the gut-brain axis, and its supposed connection to symptoms of autism. Many people assume they know what is best for autistics, and preemptively put them on restrictive diets such as gluten-free, keto, vegan, carnivore, and paleo, to name a few. Doing so with good intentions, thinking it will mitigate many of the unfavorable side effects of autism. This is, however, a slippery slope. Many autistics are known to have eating disorders and have problems eating anything substantial to begin with. They are often seen dropping weight quickly because they have sensory aversions to the majority of foods introduced to them.

I must insist that no significant research shows that a particular diet reduces how autistically a child does or does not express themselves. Nor does food consumption alone have such a miraculous effect on comorbidities like anxiety or poor sleep. I have eaten a healthy vegan diet for eight years, and I know this from experience. It wouldn't be able to be studied reliably either since we have naturally fluctuating symptoms, where our sensitivities and abilities change over time on their own with no outside cause. And if the gut-brain axis is real, its effects on comorbidities and autism are negligible at best. They should not be considered a viable solution, because attempting to push these restrictive diets only aids in dangerous weight loss for the autistic child, without making a significant difference in their symptoms. Any parent of autistic children knows that it is a miracle to find food they like in the first place. On our end, certain foods can remind us of feces, and make us sick when we dare to consume them. I want the

IACC to consider that our struggles with food are not superficial or to be taken lightly. Fad diets can seriously harm us, psychologically and physically.

Although it is not common knowledge, autistic people can experience anxiety and depression on a deeper level than neurotypical people. That is why my next suggestions are for mental illness primarily. There is a well-known spiritual symbol and plant medicine that has been used for thousands of years by the Native Americans. I have used it personally, and view it spiritually as they did. It is legal and powerfully eases both anxiety and depression. It is called amanita, and it is a GABA agonist. In my experience, it created barriers in my mind that stopped anxiety in its tracks. Amanita is stigmatized and not well known in the modern world, but pioneering the way for its use is autistic psychonaut Amanita Dreamer. I'd recommend the committee search her and psyched wellness for more information and studies. It is not accessible in Louisiana, but my next suggestion is. Which is powdered kava root. Not for people with liver problems, it also helps with anxiety and makes one talkative. For those prone to tolerance, kava only builds up in the body, getting stronger with each use. As a fair warning though, it tastes like dirty water. Not good for those with strong gag reflexes and sensory problems. I must address that, if anyone on the committee dismisses these plant medicines as quackery, please remember that many pharmaceuticals and medicines that are deemed socially acceptable originally came from nature. It is time we revisit these and use the findings to our advantage.

As a general rule, I do not generally condone aba therapy of any kind, but especially the kind meant for young children, like EIBIs. I feel it is especially deplorable to force young toddlers to conform to an ableist society that seeks to crush their sense of self and forcibly shove down their identities. A better alternative can be seen with one of my autistic baby cousins, Noah. I recently bought a chew toy for him, as he was feeling noticeably uncomfortable in his living environment. Throwing things and biting people, as it were. When he received the toy, he chewed and chewed on it without letting go. This way, not only will the damage done from his bites be all but nonexistent now, but he will also receive the many benefits of stimming and exploring his senses openly. Creating new neural pathways through which he will more comfortably examine the world. Rewarding your child for self-regulating with these behaviors is the way to go, not actively suppressing them with invasive therapies.

On a final note, I will go over a few key points I find important. Nor lead, Tylenol, pesticides, or vaccines cause autism. Autism has existed since the dawn of humanity, and none of these things existed before us. Plus we are genetic. I find it odd that the IACC won't let us criticize organizations as a part of the rules for commenting. I should have a right to voice my complaints if there are any, and that's not radical. I must also say that I have a problem with how the current DSM-5 classifies autism as a diagnosis because it leaves a lot of people who can handle themselves out in the real world and work a job as not autistic enough to qualify. Not all autistic people have it as a disability, and that is just a fact of life many refuse to accept. We are real, and we are valid. Thank you for your time.

Cindy Rieck

I think autism research should continue do that way it can be identified easier, and kids can get accommodations

Star Ford

As an autistic person I feel research should be focused on ways to achieve equality of access and opportunity for all people regardless of their level of ability or disability. The main areas of research should be in transportation, communication support, education, job accessibility, and health equity.

Elizabeth Ashby

I believe more funding is needed to help autistic teens and adults. So much funding goes towards trying to decode our genes or to try to abuse us into acting "normal" (aka ABA therapy). This needs to stop. There is nothing wrong with autism existing, and therapy and support to allow all ages to be autistic and SAFE is what is needed.

And better support for parents of autistics, as all they get is the equivalent of grief counseling. We are not burdens, no matter our support needs. And the parents deserve support and encouragement. Not fear.

Julia Heslin

My name is Julia and I am 31 year old woman with autism. As someone who was diagnosed in adulthood, I would like to see more research being done that focuses on all autistic people, not just small children, and especially research that includes girls and nonbinary persons. I would also like to see research prioritize people of color.
I believe the autistic community would be better served by research that includes and amplifies our voices, and works to make our lives better. I would like to see attention shifted away from research that focuses on the cause of autism, ways to prevent it, and techniques to modify autistic behavior, as much of it stems from a very ableist place and causes real harm to autistic people, especially children.

Research funds are better spent on studies that seek to help improve autistic people's lives.

Thanks for hearing me out!

Note: Personally Identifiable Information (PII) has been redacted from the following comment.

Alison Greathouse

Autistic people are people, too. Please stop funding Autistic Conversion Therapy, also known as Applied Behavioral Analysis or ABA.

Peer-reviewed research: https://catalystjournal.org/index.php/catalyst/article/view/29579/23427

It reads in part:
ARTICLE
Disturbing Behaviors: Ole Ivar Lovaas and the Queer History of Autism Science

Margaret F. Gibson
Renison University College, University of Waterloo [PII redacted]

Patty Douglas
Brandon University [PII redacted]

Introduction

On April 27, 2016, autistic writer and activist Amy Sequenzia posted an article on the Autism Women’s Network website entitled “Autistic Conversion Therapy.” In it, she described her reaction to the newspaper headline, “Obama calls for end to ‘conversion’ therapies for gay and transgender youth.” She agreed with the US President that any "expert" intervention that attempts to change who young people are in terms of their sexuality and gender identity is both violent and immoral. She also shifted some words around in her reading of the article to consider a similar challenge to the dominant "expert" treatment of autistic young people, Applied Behavioral Analysis (ABA). ABA is the most commonly used and funded autism intervention today that seeks to shape "normal" behaviors in autistic children while extinguishing those behaviors designated as autistic (Williams & Williams, 2011). Sequenzia posted to Facebook:

I propose that every time we write or talk about ABA, that we also write or say: Autistic Conversion Therapy. Gay Conversion Therapy has a bad reputation now, even if it still happens. Both ‘treatments’ (tortures) have the same root. I want the supporters of ABA to own their objective. ABA: Autistic Conversion Therapy that uses torturous methods. (Sequenzia, 2016)

Needless to say, this post created considerable controversy, with vehement supporters and challengers.

This paper interrogates the interwoven "root" of the therapies that Sequenzia describes as seen in the overlapping approaches to changing the behaviors of "autistic" and "gender-disturbed" children in the work of UCLA psychologist Ole Ivar Lovaas. Lovaas is widely recognized as the founder of ABA, the most commonly used and funded autism intervention today.In this article, we examine Lovaas’s published journal articles from 1965 to 1988, including his most famous ‘and still-cited‘ 1987 article which (in)famously claims that ABA therapies caused 47% of the children treated to become ?indistinguishable from their normal friends? (8).

Less commonly recognized is Lovaas’s simultaneous involvement in the Feminine Boy Project during the 1970s, where he catalogued and developed interventions into the gender and sexual non-conforming identities and behaviors of young people (Burke, 1997; Dawson, 2008; McGuire, 2016; Silberman, 2015; Yergeau, 2018). He engaged in the latter project while funding, supervising, and collaborating with his student George Rekers who continues to be a central if controversial advocate for so-called gay and trans "conversion therapies." In this lesser-known project, Lovaas catalogued and developed interventions into the gender and sexual non-conforming identities and behaviors of young people (Burke, 1997; Dawson, 2008; McGuire, 2016; Yergeau, 2018).

Here we perform a "history of the present" (Foucault, 1995) to problematize ABA as a troubling ‘even dangerous’ technique of power today. In this, we join other disability studies scholars (McGuire, 2016; Tremain, 2015) who undertake genealogies that dislodge current social arrangements and regimes of power-knowledge that naturalize particular kinds of humans (i.e., non-autistic and gender conforming) as normal and others as in need of containment and/or improvement. This article is the first occasion, to our knowledge, where a history of the present approach has been brought together with queer disability studies and autism science history.

While we do not claim that Lovaas was the only contributor to ABA or to gender-shaping behaviorism, or that the root of these two sets of practices is indeed ‘the same,’ our attention to these texts seeks to trace the work they are doing, including what ‘kinds of people’ they produce (Hacking, 2006). Through the writing of Lovaas and his co-authors, we can see the production of the un/underdeveloped autistic person who lacks full humanity without early intervention (Sinclair, 1993; Yergeau 2018); the gender non-conforming or trans child doomed to miserable exclusion without intervention (Pyne, 2016); the indispensable scientific experts and their unwavering staff members; and the freshly minted mother-therapists who were to take up home-based, boundless "development" work (Douglas, 2016; McGuire, 2016) on their autistic, gender-nonconforming or queer child.

Miyako Jones

Please allocate majority (if not all) of the funding to creating inclusive communities that help Autistic people thrive as themselves instead of funding research to force Autistic people to conform to neurotypical behavior or funding research to try and prevent Autistic people from being born. Autism is a natural part of human diversity.

Dora Csurgai

It would be great to see more awareness from doctors and nurses about diagnosing girls on the spectrum before the age of 10. Even with obvious signs of autism, many parents' concerns are not being heard because girls present differently from boys.

It would be also important to see more research about autism spectrum and gender expression/experience, including resources and education for parents. As an example, I know that many of us were surprised to discover that 70% of people with autism experiences gender and gender roles/expression in a different way, and more fluidly than others. It would be great to see data, stories, best practices about this, given that parents have a very different experience, especially if they are not autistic. I'm learning more from my own child at the moment, than from any publication and there seems to be a lack of materials for pre-teens about gender on the spectrum.

Workplaces: some tech giants already have autism supportive programs/job interviews, accepting people on the spectrum to the workplace but they are mostly software and engineer-based. It would be great to see the efficacy of these programs and their scalability to other companies.

Alivia Strong

I, as a late diagnosed autistic adult, would request there be funding sent to research how to identify autism through out more minority groups (ex: female, poc, non-christian religion, gender non-conforming, etc.) I would also suggest funding for how to best accommodate autistic individuals in various settings. I as a late diagnosed individual, received little to no workable information with my screening and diagnosis. I would also recommend a study be done to seek the connection of autism and dissociative disorders. There seems to be a correlation, though, there are little if any studies done w/ both autism and dissociative disorders.

Thank you!

Brady McBride

I am an autistic adult writing to you because I think that the Rejection Sensitivity aspect of the autistic experience that not many people know about (and, naturally, that not all autistic people experience) is criminally under-researched. A good example of what I mean is the internal, emotional reaction some autistic people may have when someone is not unambiguously excited about a prospect or assuring them nothing is wrong; for example, when someone replies with "yes." instead of "yes!" to a text, the person may perceive this as a veiled indication of annoyance with the recipient or even outright dislike of them. I myself suffer from this Rejection Sensitivity, and I have my own theories on exactly why so many autistic people share a similar instinct/response, but I am not a researcher. Henceforth I have posited the idea towards your organization.

Naomi Bishop

I would like to see research in Natural Language Processing in autistic kids and Gestalt language learners. Speech Therapy and OT as well as school programs would benefit from knowledge about Gestalt language learners.

Isaac Frandsen

I would like to request. Research into ways of helping us navigate the world while remaining ourselves

Maria Ciano

I’m a 54 year old woman that was just diagnosed a few months ago as autistic. Money needs to be spent on providing accurate information on how girls and women present with autism so we are able to get diagnosed as young as boys are being diagnosed. My life has been extremely difficult due to not knowing I was autistic until now and receiving no specialized help in learning to function in a neurotypical world. Whereas boys get diagnosed much more frequently and much earlier than girls. Again the overall medical community is doing a disservice by ignoring gender differences when it comes to autism. Money also needs to be spent in helping all autistic people in any way possible to allow us to function and lead independent, full lives with our differences. Money also needs to be spent educating the public on the fact that autism is GENETIC and that there is no ‘CURE’ for it. The public needs to accept this fact. Applied behavioral analysis and other abusive treatments need to be outlawed to stop forcing autistics to mask what is normal behavior for them which causes a great deal of stress and burnout. The positive traits of autistics also need to be brought to the public eye instead of only discussing the struggles of autistics. I’m proud to be autistic!

Freya Harris

Right now, research funding on autism and other neurodivergence still disproportionately focuses on behavioral therapies, biomedical studies, causation and “prevention.” Research on autism should reflect what the autistic community truly needs: understanding, and how to help autistic children cope and interact with the real world.

Autism is not a disease that needs to be cured. It is a difference that needs to be understood.

Chris Leah

As an autistic adult, I feel that more funding needs to go towards supporting autistic people as they are instead of trying to fund research for finding a cause or cure for something that isn't a disease. I think the nonverbal community needs more funding to support robust communication systems and devices so that they can speak for themselves instead of having their wishes, wants, or needs assumed. I think there should also be more study on comorbidities, such as the GI issues that many autistic people face, to find better treatments for these conditions. More focus should be placed on helping autistic individuals find meaningful employment and access to those jobs in whatever way they need to be supported such as an autistic person who cannot drive having access to reliable transportation. Funding should focus on supporting autistic people as they are instead of trying to force us to behave as though we are not autistic which may be more comfortable for others, but worsens our anxiety and depression. Emphasis should be placed on providing for low-income families who cannot afford therapy or counseling, and these practices should be Neurodiversity affirming.

Meg Hartley

I'm writing today as an autistic person regarding how autistic research money is spent. I'm tired of people trying to "cure" us, and I'm tired of the vast majority of money being spent on studying children when most of a person's life is in adulthood. We don't grow out of it. We're taught to act allistic, and burn our sensitive neurology out on it -- we shouldn't be expected to die before 60, research money needs to be spent on how society can better integrate us AS US, allowing us to live full AUTISTIC lives -- different is okay. My sticking my neck forward and sitting funny while needing soothing lighting and music while writing doesn't these words less relevant, but it certainly made me less relevant in office spaces.

Neurotypical and allistic people need to be taught how to accept US, we're a natural part of human diversity and if society would give us a chance to shine AS WE ARE we have a whole lot to contribute. And not just in tech!!! A study about creativity in autistic people would be great, how our nonlinear thinking styles can be used productively, how our unique observations could be used productively (consulting?), a study about how to prevent autistic burnout from stealing our functionality would be great, how autism presents in females and marginalized/underdiagnosed groups, or, perhaps especially, how to prepare the allistic community to better communicate with neurodivergent people at large -- it's mostly about fully listening to the content of words and not making assumptions based on surface-level observations, learning to ask a follow-up question before writing people off. These things create miscommunication in all people (and cost A LOT of $$), but it's especially problematic with allistic/autistic communication.

"Normal" isn't a thing. Research needs to stop revolving around it. Kids become adults, and then we stay adults. Research needs to stop revolving around kids.

Ariella Lilien

I'm an adult with autism.

I think that fewer resources should be spent on researching the causes of autism (there's already a multitude of studies about this topic, and the focus on studying this to the extent of anything else carries with it the implication that stopping autistic people from existing is more important than actually helping autistic people).

Instead, those resources should be spent on research that will help improve the lives of autistic people, such as the executive functioning problems that many of us have. I personally struggle heavily in academic environments because I can't concentrate on assignments and have procrastination issues to a debilitating extent. Most medication to improve focus was developed for people with ADHD, which functions differently than autism.

If there were more research into strategies or medications to help autistic people overcome executive functioning difficulties, that would help significantly more autistic people than any research that attempts to discover what causes autistic people to exist (with the thinly-veiled motivation of ensuring we cease to do so).

Thank you for your time!

Marja Erwin

I would like to see more research into safety and accessibility for autistic people, and neurodivergent people in general. At present, many public spaces, crosswalks, public transportation systems, and so on can be unsafe and inaccessible for people who are sensitive to flashing lights.

Karen McWay

Autism research should be focused on helping autistic people live in community, w the resources they need to thrive in school & at work. Funds should NOT be allocated for eugenic research or autism cures, as those who "think outside the box" are responsible for much of the creative innovation in our society.

Alexandra Maher

Research the possible harm or drawbacks of current intervention methods, including aba. Do the outcomes the interventions are aiming for match what autistic people want?

Research the disparity in diagnosis and supports for autistic people who are members of marginalized groups, such as people of color, immigrants, LGBTQAI individuals, and those with other physical, psychiatric and developmental diagnoses.

Research into how trauma and autism may interact. Research into life satisfaction of those with autism. Rates of abuse or mistreatment, and how these can be lowered.

Meg Perine

I just saw another headline the other day mentioning the "symptoms of autism". Autism is not a disease. If the people studying it are looking at everything starting with the false premise that autism is a disease, everything conclusion they come to is also false.

Alison Stanton

First and foremost, I think the most needed Autism-related research is about how to assist neurotypicals in interacting with Autistics in a respectful manner. Framing Autistics as the problem dooms Autism research to perpetuate stereotypes, inequalities, harmful therapies, and sub-par supports for Autistics. Instead, we must recognize and find ways to assist neurotypicals to be thoughtful about what they are bothered by, flexible in their communications, inclusive in their activities, to understand and value consent, and how to accept differences overall. All of those items also have broad applicability outside of Autism research as well.

Second, how do we make sure that cis and trans female and non-binary Autistic youth are identified and supported when they are young? The number of non-cis-men("Women") who learn they are Autistic later in life or never know that about themselves is unacceptable. Societal stereotypes about the Autism Spectrum deprive some of the most capable members of society from having a framework and the various skills necessary to interact with the world as it exists today. At the moment, Twitter, Instagram, and other online content on "Women" Autistics by "Women" Autistics is better education for Autistics and their loved ones than anything the medical community could dream of. ("Wait, that's not just me?!" and "That's a great coping mechanism. I'm going to try that." and "OMG, why didn't anyone bother to tell me that 20 years ago?!")

Third, we must do research to help and support Autistic adults. Unlike the foster system, you can't "age out" of Autism at 18 - though the dearth of adult Autism research tries to make it appear that way.

Fourth, we must require the collection of SSOGIE data in all research. SSOGIE stands for Sex, Sexual Orientation, Gender Identity, and Expression, though it's also known as SSOGI, SOGI, and SOGIE data. As a professional in data engineering, an LGBTQIA advocate, and someone who has been part of SOGI data collection work, I believe these key elements of understanding (health) disparities should be part of all standard demographic data collection. Though I am also reminded that I saw a research article title about how there is a noticeable overlap of Autistic and Trans identities and my first response was "Where you been? You needed a study for that? Duh. At the very least: combinatorics." A large portion of the smartest people I know are both Trans and neurodiverse. The ways the intersections of those identities have negatively impacted their lives is dramatic. We need data to be able to identify how to reduce these disparities.

Fifth, we must ensure that zero research funding goes to "curing" Autism. Autism can't be cured and if Autism elimination could be done it would be unethical to do so.

Sixth, we must ensure that zero research funding goes to understanding a nature versus nurture causation of Autism. That means, among other things, that no research funding goes to anything related to genetic information.

Seventh, research into how to improve the sleep Autistics get and how sleep disorders impact Autism is a frontier for research that deserves priority. This research avenue may have the best potential for quality of life improvements.

I'm happy to elaborate on any of my remarks. If you would like to discuss them or anything else on this topic you can reach me at this email address. Thank you for your consideration.

Shelley Hendrix McLaughlin

My son is approaching 27 years of age. He was diagnosed with autism at 22 months of age - a quarter of a century ago. His inability to communicate verbally at the time was surpassed with his ability to speak to us with his physical behavior and underlying medical condition (output/input). He has long communicated bio-behaviorally.

We had fairly quick access to speech therapy and sensory integration occupational therapy. He did not have access to appropriate ABA therapy until after legislation was passed in the state of Louisiana in 2008. Even after legislation was passed, it took too many years for the implementation and volume of BCBAs to grow in our state for him to receive this form of therapy. All forms of behavioral health treatment were implemented as best we could from a homegrown standpoint thanks to Catherine Maurice's workbook and some LSU students.

We did have access to physical health insurance, but our practitioners would largely dismiss any physical health concerns that we had by stating repeatedly: "Children with autism just have ____________." My son had diarrhea for four straight years, and we could not secure a gastrointestinal scope/biopsy or appropriate stool culture for him in the United States. After we went out of the country for those diagnostics, we were given a treatment plan which alleviated the issues in less than 5 months.

He was then able to be effectively potty trained.

I continue to work with parents of children who are newly diagnosed (within the last five years) and statements like the ones above continue to occur and specifically continue to occur regarding gastrointestinal problems found in ASD individuals, despite the body of science that has been developed since 1998. This is concerning because the awareness is not reaching both pediatricians AND gastroenterologists. Still.

My questions are: When children who do not have autism have the same physical health issues are they also untreated for that very diagnosable condition? If not, what makes my child's health concerns different?

We have struggled with this for the last 25 years from his gastrointestinal issues to the genetic polymorphisms that are affordably treatable that our physicians dismissed. We have fought to have X-rays when we know that it is not his autism "gait" causing him to walk that way and twice have discovered hairline fractures in his feet that were causing him to walk that way. He struggled for 6 months with aggressive behaviors for which he constantly apologized and communicated as best he could to tell us what the problem was.

Over and over, we heard this from him: “Tigers are eating my brain.”

So, his primary care physician referred him to a psychiatrist, who found him to have ASD and offered to put him on SSRI’s.

We politely declined and were referred to a psychologist to ensure he wasn’t feeling sad with his transition from high school to the real world. Perhaps he just had no sense of life direction causing depression. We argued that what he was experiencing was not any delayed coming of age issue, but the box had to be checked anyway. The psychologist recommended cognitive behavioral treatment.

Our next referral was to a neurologist who did an MRI and also prescribed SSRIs. When we politely declined SSRIs for a second time, he suggested we supplement with vitamin B2.

Aggressions we had not seen since he was 3 or 4 had erupted. He could not sleep. He would not eat normally. He was in pain and no specialist could determine why that was. All the specialists saw was the autism and not the underlying physical health issue causing the behaviors.

Finally, my son said it mostly hurt by his ear, right where his upper and lower jaw connect.

I suddenly remembered that we had gotten a new retainer in May. It was now October. I thought perhaps it is causing TMJ, so I scheduled an appointment with his orthodontist.

The orthodontist looked in his mouth and said in less than 10 seconds, with no diagnostic instrumentation, that all four of his wisdom teeth had come in - sideways. They were pressing on his rear molars. X-rays showed us that their eruption had eroded up to half of his existing molars from the rear. He had four large abscess infections at the back of his mouth.

He had to undergo several rounds of antibiotics to clear up the infections while we worked to secure approval by Medicaid to have his wisdom teeth extracted before he aged out at 21. Administering the antibiotics did not relieve the pain of the teeth grinding together however.

As soon as his wisdom teeth and rear molars were removed, his behaviors immediately resolved. As soon as the anesthesia began to wear off, he just kept saying thank you, thank you!

No ABA would have solved this issue as there is no command for stop having 4 tooth abscesses.

No psychological treatment would have solved this issue because psych meds and clinical therapeutic discussions do not resolve severe dental health issues and bacterial abscess infections.

Using an MRI as a diagnostic tool did not resolve this issue, because it was not a brain issue.

Our children with ASD often communicate with behaviors and biometrics to explain what they are experiencing.

How can we work together to impact Medicaid and Commercial health insurance policies to develop protocols that will address:

- Improved health outcomes for individuals with ASD across the lifespan
- Screening and diagnosis of both children and adults
- Behavioral and other therapeutic approaches
- Primary & Preventive care
- Communication challenges in general, but especially health care settings
- Aggression, self-injury, elopement, and other behavioral issues
- Emergency room visits
- Acute care hospitalization
- Treatment for co-occurring physical and mental health conditions
- Premature Mortality
- Medical Practitioner Training
- Caregiver Mental Health

- How can we work together to ensure a federal program such as Medicaid, which is implemented by the states, is portable between states and still maintain the integrity of the state’s rights to implement their own program?

- How can we work together to ensure that Medicaid provides physical health care for our individuals with intellectual disabilities and developmental disabilities after the age of 21 - including dental, vision and hearing - since their teeth, eyes and ears are also still located on their united physical body?

- How can we work together to discern underlying symptoms and treat them with expediency and efficacy?

- How can we work together to implement an appropriate physical health plan during the otherwise wasted "wait list" years as we wait for our children to have their adverse behaviors addressed?

- How can we work together to effectively explain to physicians and health experts that for all their areas of specialty, each one of our children has a specialist located within their own family who has memorized their behavior patterns?
    - Or determined their function of communication?
    - Or deeply observed their moods?
    - Or analyzed the consistency of their bowel habits?
    - Or ascertained a change in their volume of phlegm?
    - Or the development of a new skin condition?
    - Or noted their reactions to sensory stimuli of sounds, tastes, and smells?

Who is the person in the room that is the expert on the individual with ASD in the room and why are they repeatedly unheard by the medical establishment, especially when the specialist has spent less than a day with them, or even less than an hour?

How can we help both caregiver and individual with ASD be better heard in these arenas?

I am, along with so many other family members and people with ASD, eager to work with the IACC to develop solutions which are easy and effective to implement with our front-line pediatrics and primary care physicians. Delays in basic treatment lead to more expensive health issues and management of those issues.

I thank you for the opportunity to speak to this both with and for him. He can tell you the story of what he endured with his wisdom tooth incident himself. He was frustrated, but he was also incredibly patient considering the amount of time it took us to understand what it meant when he said that he had tigers that were eating his brain to describe the headache which was a secondary pain referral from a horrific dental situation.

Thank you for the opportunity to speak to this and let you know there are hundreds of thousands of other families struggling with the same concerns, issues, and lack of appropriate and adequate basic health care for our children and adults with autism, because they have autism.

Mostly, thank you for listening!

Jessy Rice

There's a lot of controversy surrounding the push to find a cure for autism. Most of us who are autistic are very against finding a cure, while a large number of neurotypical people are for finding a cure. I would be interested in knowing (from a psychological standpoint) if the autistic people who do want to be cured want this for themselves or if they want this because the people around them think they should want this. In other words, of the minority of us who might actually want this to happen, why?

Note: The following comment contains sensitive language. Personally Identifiable Information (PII) has been redacted from the following comment.

Anna Gray

Please research destructive effects of loud noise on Autistics with hypersensory perception and develop law drafts to be implemented at the federal level and by each state and territory. Existing noise regulations are incredibly ableist and require a person to be half-deaf in order to exist successfully in most places. All of the loudest sources of noise are excluded from the decibel limits. Aviation, trains, construction, lawn mowers, leaf blowers, tree shredders, traffic, and so on. It is as to say that all crime against women is prohibited, except for rape and murder. Decibel limits themselves are very ableist. Where I live it is 65 Db during the day. I develop sensory overload after 60 Db. I am not safe where I live. There are multiple studies that indicate anything over 35 Db is unnatural, causes stress, premature organ wear, and shorter lifespan. Yet, neurotypical people continue to make loud noise.

I have 1 mile hearing range when my perception is triggered. On the logarithmic decibel scale, my hearing is 80,000 times more sensitive than that of a neurotypical person. What is 85 Db to a neurotypical, is 140+ Db to me. Being suddenly subjected to a loud noise causes me to develop sensory overload. In the past, I had a stroke from severe sensory overload. Noise also causes me to develop a number of severe physical and neurological symptoms, including heart and blood pressure problems, headache, dizziness, nausea, severe abdominal pain, inability to focus my eyes, confusion, loss of spatial orientation, cognitive, executive, and memory failure.

I have suffered mentally, physically, and emotionally from being continuously exposed to aviation and train noise. Since regulations are ableist and everyone refused to help, I became suicidal. I used to have IQ of 187. It is now 129. I used to have photographic memory. It is now barely works, and my intellect is 100% memory based. So, no memory - no intellect. I am having visual and audio hallucinations. I am becoming non-verbal again and losing ability to speak because this ability is also memory-based. I have not been able to earn income lately.

Do not let other Autistics suffer like I did. Over 60% of us have noise sensitivity. My spouse is a noise sensitive Autistic. If you want help with this study, please reach out to us using this email or his phone number [PII redacted]. I cannot successfully talk on the phone.

Do the research and act on it, do not wait.

Thank you for reading this.

Note: Personally Identifiable Information (PII) has been redacted from the following comment.

Wensheng Li, Ph.D.

My name is Wensheng Li. I have a Ph.D in chemistry and current work as a scientist in an research-based company in St. Louis, MO.

I have a daughter with autism. I am also the founding director of a nonprofit organization, Xiaoyaya Autism Initiative with a mission to advocate the science of autism and to help individuals with autism reach their full potential.

Name: Wensheng Li, Ph.D

[PII redacted]

Priority 1: Construct an inclusive autism community

In the last few years, the neurodiversity movement plays a big role in changing the bias and stigma toward autism community. However, a hot debate has been observed between some neurodiversity advocates and some parents with loved ones need more support, or the profound autism advocates. The two groups almost disagree on every aspect including, but not limited to research, intervention/education, supporting system. The autism community is very divided.

But no matter how much the two groups are against each other, one common goal is to build a world that is more inclusive and respect the autism community. If the autism community couldn't respect each other and be exclusive, not inclusive, it would be difficult to ask others to be inclusive and respectful.

With this said, one priority for IACC is to research on finding the common ground for the autism community including how to define autism, what languages should be used to describe autistic individuals, what lifespan supports are urgent for individuals.

One thing is clear to me is that autism is a difference, a disability and disorder. The community must respect the difference, accept the concept of disability, and work together to change the world to minimize the disorder.

Priority 2: Limit the association research, but more biomedical research

It should clear to everyone that, biomedical research is not intend to “cure” autism. Autistic traits are more like everyone’s personality, and it is hard to change an individual’s personality. But it should be also clear to everyone that, medication is needed for better help those experiencing anxiety, irritation, self-injury, aggressive behaviors, et al.

One other aspect of biomedical research is to limit those association research, but more causal research if there is any. Research like the association between parental age, pregnancy factors, maternal medications, et al and autism risk should not be supported, at least minimize the support. This kind of research is not only useless, but also very misleading.

If a couple want to have baby at older age, it is their decision. If there is a complication during pregnancy, the important thing is to make sure both mother and baby be safe. Autism risk shouldn’t have a factor for families and doctors to make the right decision.

Priority 3: define subgroups of the autism spectrum disorder

It is obvious that, different individuals require different intervention/education model and different levels of support. There would never be one model fits all and that is why we advocate the neurodiversity concept. It is therefore important to define different subgroups under the umbrella of ASD and design different education and supporting models to meet the needs of the whole community. The level and type of supports for those with no verbal communication would be different from those who could communicate with words.

Research should be prioritized to define different subgroups based on either genetic information or different behaviors. This would be best to find the right solutions for different individuals and distribute the resources to those in need.

Katherine Marchant

Applied Behavior Analysis is currently the primary intervention for Autism Spectrum Disorder, but research studies and the voices of many autistic people have brought to light that ABA can be traumatic and painful for autistic people. Interventions such as play therapy have been researched and proven to be an effective intervention for autism spectrum disorder. I implore you to listen to the voices of autistic people, and use resources to help understand and support autistic people rather than try to “cure” them or prevent autism.

Lisa Sosnowski

There is a need to establish separate developmental milestones for autistic children. The current neurotypical milestones do not take into account that autistic brains are differently wired. These milestones should be developed in collaboration with autistic adults. In many cases these children are not behind, they just develop at a different pace and learn differently than their neurotypical peers. As the famous quote attributed to Albert Einstein states "Everybody is a genius but if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid"

Desiree Enos

Autism research should be focused on effective accommodations for autistic children and adults. Autism is a neurotype that naturally occurs in the human population; it is not a problem that should be eliminated, and autistic people are worthy, have human rights, and deserve respect and appreciation- not to be eliminated from the human population. Everyone benefits when autistic people thrive, and research priorities should reflect that.

Fred Madrid

Our Military Service members face unique challenges as they often have requirements to serve in different parts of the country or overseas and this can happen once every 1 to 3 years. One of the largest challenges that can have significant impact on the family and children with ASD is having to restart services. Restarting times and delays can vary depending on the location and this often leads to a serious degradation of any gains a child might have previously made. Other challenges come with the Health Insurance carrier as this too can vary from location to location. In review of certain programs like TEFRA which looks to be managed in different ways from state to state this often tends to also add an obstacle for our Uniformed personnel and their children as they might not quality or could require a process that adds to the delays in access to care.

**What measures have been considered to provide for a more standardized process where in which these children can have better opportunities at Access with minimal delay?

**Department of Education in some states have also struggled with having the capability to provide these services. Has there been any additional consideration in seeing how to assist DOE across the country to meet this requirement?

Nicole Corrado

While there is training for first responders regarding autism, particularly information on children who wander, there is not enough training done by or in collaboration with autistic persons, especially teenagers and adults. Many studies on autism and first responders only looks at statistics, outcomes, and only looks at the responder and caregiver perspective. A lot of misinformation continues to be in training programs. Certain programs, like autism registries, and tracking devices, fail when the responders are misinformed or not informed at all. It is far more effective for police, fire, and ambulance services to communicate with autistic persons who have lived experience with first responders. One example is a retired autistic firefighter in Canada who talks about autism to other first responders. Another example would be to have an autistic civilian who has had recent interactions with first responders join an advisory committee (Mental Health Board, Missing and Missed Implementation Team, etc) to discuss their experience with the first responder agency.

Daniel Bevagna

I am a 28-year-old autistic male. Currently, IACC research funding on autism disproportionately focuses on behavioral therapies, biomedical studies, and causation and/or ‘prevention.’ As an autistic, who lives daily with this condition. causation, behavioral therapies, and biomedical study research do nothing to improve my quality of life. I personally believe that autism research should primarily focus on improving our quality of life by facilitating our ability to navigate effectively within a neurotypical world. This would entail concentrating on cutting-edge technologies and novel teaching methods reinforced by a reliable and consistent framework of individualized supports to maximize our ability to learn and to fully partake in today's society. About 1 in 44 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC?s Autism and Developmental Disabilities Monitoring (ADDM) Network. Our numbers will only continue to grow. Doesn't it make sense to concentrate research efforts on actually helping autistics thrive in our society rather than fixating on "curing" or "eliminating" the condition altogether?

Research, Services, and Supports for Adults with Autism

Eileen Nicole Simon, R.N., Ph.D.

Wearing a Necktie?

I visited my son's school many years ago. Students discussed what they wanted to do in life.

"I love airplanes. I want to be a stewardess when I grow up," one young girl offered.

"It's cars that I love," my son replied. When I grow up I want to drive to work, and wear a necktie, like my father."

While a patient at Westborough State Hospital in Massachusetts, my son was employed at the Agnes Clarke Memorial Workshop. He assembled and packaged products to be sold in stores. He was paid for each completed package, and this was an incentive for him to work quickly.

Unemployment since his discharge from Westborough (in 2003) has been the worst aspect of my son's "community" placement.

Is there anything the IACC could do to encourage states to increase funding for care of autistic people in the community? The idea that mothers should provide "community care" is wrong. Why do children move out of their parents' house when they reach adulthood?

Emma Sloan

Please prioritize research on ADULTS with autism! Especially the following areas:

1. Physiological differences in autistic people/physical health issues faced by autistic people (GI disorders, dysautonomia, immune differences, etc).

2. The physiological basis of autistic burnout and how people who experience autistic burnout can recover functioning.

3. The autistic aging experience and the physical and social needs of elders with autism

4. The needs of AFAB adults with autism, including stuff like how autistic people experience pregnancy and menopause

Rachel Braun

As an autistic adult, I would like autism research to move away from prevention and behavioral therapies and more about ways to best integrate autistic people into society so we can live our best lives. This can include but is not limited to housing, education, healthcare, and employment. As an autistic adult, one thing that has changed my life was an employment program that was created specifically for neurodivergent people. If there can be research to make more of these programs and to make them the best they can be that would be wonderful.

Benjamin Moore, B.S.W., CFRS, CRS, CPS

Good morning, I would like to point out the need for Adult Drop-in Centers in the Philadelphia Communities. Day Programs are scarce in my city. In addition,it would be awesome to see more resources allocated towards Transition Pathways to Higher Education & Independent living arrangements. We need better certification Peer Mentor & Peer Navigators with lived experience in Philadelphia. Training for Community Autism Peer Specialists & Certified Autism Peer Specialists are highly needed in Philadelphia. These types of opportunities gives us the capacity to work more effectively with other peers on the Spectrum or who have Intellectual Disabilities.

Daniele Colozzi

I think the autistic community has been neglected in many ways! There are nothing designed specifically for adults with autism! Autism is so complex, it is on a spectrum! So the variety of cases go by the thousands! Autistic people surely fall through the cracks! As they get older, so do their parents! Then they will be alone in a world they don?t understand and most likely will end up in prison or homeless! It is so unfair, and very sad. We need to meet their needs! We can do better, we need to do better!

Brittany Daniels

As an autistic woman with four other diagnosis outside of autism, I would like research done on autistic college students like me who learn best with written instructions at the same time as charts, examples (at least 3 to 4 different examples), graphs, images, screenshots (when teaching me how to use new to me apps/software) and/or written step by step instructions with examples (3 to 4 different examples), images, photos, screenshots (when it comes to teaching me how to use new to me apps/softwares) at every step of the written down step by step instructions and why it is difficult to get this reasonable accommodation at the college/university level and if we are able to get this reasonable accommodation why instructors of online and/or in person college/university classes don?t want to give this reasonable accommodation and/or refuse to give this reasonable accommodation despite it being a reasonable accommodation on their reasonable accommodation letter given to each instructor they are going to take a class from.

Lauren Janas

I would love to see much more research focusing on what adults with autism can do to thrive and adapt to the outside world. Most research seems to be focused on children, but with new resources and communities on the internet, more and more people are discovering they are autistic in their adulthood and there is almost no research or resources to support them. This is especially true for women who tend to be underdiagnosed. I would also love to see more research on accommodations that can be provided to help autistic people thrive, rather than prevention/cures. Thank you!

Alexandra Gass

I would like to see more research into the efficacy and implementation of interventions in older teenagers and adults with autism, in particular community integration efforts and the long-term effects of early interventions such as Applied Behavioral Analysis.

Ian Muse

We need more services for adults, especially those diagnosed late in life. We are struggling, and we are not well. The system is failing us, and we desperately need help.

Julia Clausen

I would love to see more research on and funding for quality of life for children and adults with autism and their families, particularly transitioning out of education-based supports into adulthood.

Jason Brown

As ASD folks get older it's much harder to make it through the day. Please help with assistance and guidance for those who reach a perma-burn type experience and those who lose caretakers.

Not everyone with ASD is in a supportive work or life environment. Last meeting I heard some minimization of a study by highlighting successful engineers' lifespan and not considering the people disabled by ASD who live in the shadows. I thought that was poor form. I don't want to limit anyone's speech I am just providing another perspective. I don't have data to back my claim but for each individual engineer I would imagine the ratio would be several more disabled people living in poverty.

Susan Robins

As the mother of a 20yo autistic man who also has LGS epilepsy, I am frustrated by the lack of quality support services required of states by the federal government.

I live in Illinois, a state that provides the bare minimum of support funding. Those lucky enough to receive the home-based Medicaid waiver receive the same amount regardless of their support needs. This means our state has no quality day supports for disabled individuals requiring 3:1-1:1 support. Additionally, the red tape our state has makes it hard to create quality private programs that could mesh with government funding. Supports out of the home for those with high support needs are pushed toward ICFs, an environment undesirable to my son and to us. We want him to be part of his community. He thrives this way.

The lack of portability of services across state lines is another frustration. A sibling who will be the point person of managing care down the road should be able to move for careers if desired. Being frozen in the state where the disabled sibling receives services is very limiting to them.

In short, I’d like to see more money earmarked toward those with high support needs and portability across state lines for these services.

Alicia Arellanes

I would like to see more autism research of autistic adults, autistic women, autistic people of color, and autistic people who are nonbinary or trans. I would like to see research that focuses on how autistic people communicate whether the communication is done verbally or not.

Trigger Warning: The comment below contains reference to abuse, the criminal justice system, and other sensitive topics.

Philip Harlow

I'm Philip Harlow and I am Autistic and have Sensory processing disorder and PTSD and I was ward of the state of Texas in CPS custody and went to five different high schools being bounced around from different group homes to group homes to boys ranch. I Still remember in one of the group boys homes I was in where there was widespread abuse one of the boys died, to this day this still hurts me and bothers me, the things that I have seen and witnessed as a boy in the CPS Foster Care system. I felt like I had no voice, and if I ever spoke up I would get retaliated against and abused more. I have always felt even as a child that the state of Texas is broken and felt no one cares I am just a worthless pebble on the street or number. After experiencing a traumatic life in the Texas foster care system and abuse I was pushed through high School exempt from all tests and just passed through until I graduated from high school and I was emancipated from CPS and the state of Texas. They basically just open the door and throw you out on your own and I suffered through homelessness and severe marginalization and for the trauma and abuse continued. Because I qualified for Medicaid and Medicare and disability income I was lucky to be able to get section 8 voucher and get an apartment for myself. As an artistic adult male I suffered through and continue to suffer through severe discrimination, stereotypes and bullying and also intimidation by apartment management and neighbors for being different and being on welfare and getting benefits and not working because I am disabled. Management and neighbors and those in authority take advantage of the fact that I have been low income and have limited means and know that I cannot afford advocacy and exploit my situation and behave predatorial. In Wichita Falls, Texas there's virtually no advocacy for disabled adult males and those in authority are aware of this and it works to their advantage. One of the worst laws I feel was ever written was the violence against women act, it is a predatorial and a vindictively written law that is used as a tool to harass, retaliate and intimidate and get back at disabled adult males like myself. I have been threatened with the violence against women's act by management and neighbors when they have tried to get rid of me because I am disabled (different) and they're looking for a way, a tool to get rid of me and get me kicked off section 8 and other benefits. This is an act when management and or neighbors are hunting someone. Police and others in authority often play a part in this predatorial behavior. I live alone by myself and have no family, I often get bullied and harassed due to my disability because I have difficulty communicating with others and lots of times freeze and my brain locks up and I do not know what to say and I have been labeled and called names like weird, strange, retard, nut job, welfare leech, and asked when am I going to get off the government tit? by apartment management and neighbors and those in authority. Being a disabled adult, extremely low income person on a very limited budget on disability I have a lot to lose. The Wichita Falls, Texas Police department have a broken, predatorial program that is extremely predatorial called the Crime Free Housing Program. The Wichita Falls, Texas Police Crime Free Housing Program is a program where Wichita Falls Police department encourages Apartment Complex in Wichita County to join their Crime Free Housing Program and encourages Apartment Complexes to join their Crime Free Housing Program and gives Apartment Complexes incentives to join their program and anytime the police are called on a tenant or a tenant comes in contact with the police the police fill out a yellow card on that tenant also called a contact card. If a tenant gets three yellow cards or contact cards they can be evicted, no matter what it does not matter. So if a neighbor or someone does not like a tenant and is trying to use the police as a tool to punish a tenant or get rid of a tenant, all they have to do is call the police and a yellow card is issued and after three yellow cards an innocent person, a tenant can become evicted and lose their home, their apartment. Also all this takes is a crooked police officer or a bad police officer that is vindictive and a vindictive neighbor and if a tenant is on section 8 they can be kicked off section 8 and lose their voucher benefit and which can lead to homelessness. There are and lots of times tenants that do not have section 8 that are either jealous that another tenant has section 8 or is so extremely conservative that they hate disabled adult males people that are on welfare or section 8 and will try to get them kicked off their benefits. I feel this is a bad program and detrimental to disabled adults with Autisms civil rights and civil liberties. I feel that it's not due to ignorance toward disabilities but it is there are some people that just do not care about others that are disabled and are cold-hearted and have a hate and judgmental toward people that get welfare benefits. I have found that this is often the case with conservatives and Republicans. I have experienced as an adult with Autism and that is disabled that the Americans with Disability Act often gets ignored and violated and no one follows the ADA especially if you are a disabled person with an Invisible Disability and you're not in a wheelchair. I feel like the ADA needs to be rewritten and overhauled, I feel the ADA is extremely weak and not specific enough and doesn't include people with invisible disabilities enough and have specifics and housing and section 8 laws and in the community in private businesses and restaurants. As an adult male with Autism I have suffered and endured intense discrimination, bullying in this treatment by those who are supposed to protect me. Discrimination in section 8 housing by landlord and management and neighbors those in authority towards disabled people is widespread and real and has been allowed to flourish and grow and continue to take place and happen under Governor Greg Abbott's predatorial and failed leadership and former Republican governors discriminatory and failed leadership that empowers enables predatorial, discriminatorial behavior. There has to be strict, drastic, severe change and consequences to protect Autistic disabled adults and invisible disability and consequences and accountability and created in a thoughtful manner. I am the way God made me and I cannot change the way I was made. I cannot change my disabilities and become neurotypical. Autistic males and disabled males with indivisible disabilities are the most underserved population in the state of Texas. Especially Autistic males who have been emancipated from the Texas CPS foster care system and have No family and no support group. For an autistic adult male like myself I have no way to get a social worker or have a caseworker. There is no option in the state of Texas for myself to have a caseworker or social worker for help navigating difficult and abusive situations. There is no state agency that will get involved or advocacy that will get involved if it does not involve family. The only way a state agency or advocacy will get involved if it is family members abuse and I have no family. The local adult protective Services treats me like I am a burden and wasting their time and say they cannot help me do not reach back out. And then a PS complains about me to the apartment management and authorities telling them what I said and then I get retaliated against even worse. After I was emancipated from CPS custody, I became homeless I was falsely accused and arrested and did not know what to do and was confused and bewildered and docile. I was taking advantage of by the police and the DA, district attorney's office and they told me that I should plead nolo contendere and I did not know what that meant and they told me that it meant that I am not guilty so I agreed and went along with what they suggested. I realize now that they were deceiving me and taking advantage of me and I made the worst mistake of my life. Today I have an assault family violence, causing bodily injury on my records and on my name, where my older half brother told the police that I pushed him and his back was hurting. One of the police officers went to school or high school with my older half brother and they knew each other. This record on my name and Stain haunts me everyday. Thank you.

Inclusion of Autistic Perspectives in Research

Brandon Germer

There is a disconnect between the Autism research that is funded and the research that the Autism community itself wants and needs. Specifically, a large amount of research is still focused on "prevention", which is of no interest to the Autistic community. We believe Autism is a perfectly legitimate expression of the human genome, and the life experience of people in this community and their advocates is unquestionably valid. Additionally, what we can offer to the world is unique and extremely valuable, though I'd argue even if we had nothing of value to offer to the commercial world it would not detract from our right to exist or the validity of our existence.

What the Autism community and neurotypical society both need are insights and actionable tools to enrich life. One way to approach this is improving the startling unemployment statistics of Autistic adults from the perspective of both the individual and organizations. Can we help companies better understand Autistic people to reduce hiring manager bias, offer reasonable accommodations, positively evolve ways of working and culture, and ultimately help companies and Autistic people thrive? Can we offer pragmatic tools to Autistic adults to more safely navigate the jungle of the corporate world?

With great research and the right partners, we can work to solve the problem that needs to be solved by reducing barriers and building connection and understanding, rather than continuing to invest in solving a problem that is no problem.

Nicholas Greaves

Hi I have autism as well and I will like to deliver a voice (to start somewhere) I fo not approve of how they are marginalized and miss understood, one of my advice is to include all the low functioning and the worst severity, find ways to communicate in a way they can understand while helping them communicate, and no therapies that harm them for this so called "treatment" while it will make thier mental state worse, try to find ways to actually make a big change. If a change fails or goes wrong, try something new that will work out, if it ends up the same, rinse and repeat until you finally succeed.

Amy Hitchcock

We have a responsibility to tell the government what research should be prioritized and where the gaps in funding are.
The autistic community needs to make our voices heard in these decisions. Nothing About Us Without Us!

Jennifer Natalya Fink

Autism research MUST reflect the priorities of autistic people. Autistic people must be centered as researchers as well as subjects of research. Instead of the 'eradicate and treat' model, research into the best ways to make society more accessible is key.

Paityn Bowen

The autistic community is so tired of the "research" about us being rooted in the neurotypical perspective of autism, which makes autism research incredibly biased and ableist. It's amazing how few people think to ask the autistic community when they have a question about our disability/neurotype.

Autism "research" is done almost exclusively from the neurotypical perspective, which not only leads to inaccurate and biased conclusions, but further perpetuates the cycle of silencing autistic people. The autistic community wants so badly to be heard.

Alex Sprague

It must never be about us without us. Neurotypical groups have constantly made stuff up about the autism spectrum over the generations. It has to stop now!

Kathleen Brennan

I urge the IACC to direct a greater amount of research towards organizations led by autistic people, which take account of the self-direction and diversity of autistic people, including people of color and women and non-binary people. Research should be driven by the needs of autistic people, including autistic adults and families with autistic parents and children. Traditionally, autism research has painted autism as something to be avoided or "cured", but in actuality, research could be used to help understand how to change society to enable autistic people to live authentically and have the supports that they need to thrive.

Ani Moller

I'm autistic, and an autism advocate on social media (Professional Audie). I read a lot of autism research and am disappointed by a good proportion of it - specifically the research that has no autistic contributors or reviewers. A lot of it is stigmatising, or views the data in the wrong way (e.g. correlation vs causation). We need principles that all autism researchers should uphold, and one of them should be that all research needs to have autistic people involved in some way.

Keira Crone

More funding should go to autistic researchers themselves.

Frederick Grossman

As a person on the Autistic Spectrum, I see little research being done that meets my needs. You must include those on the Spectrum on approval committee and don't fund proposals tjhat don't serve our needs.

Elliott Walker

I believe that greater focus should be given to creating more accessible spaces for autistic folks in research. Finding reasonable accommodations for sensory and social situations should be a priority.

Rachel Hedin

We need to listen to autistic people first and foremost about autism treatment and research. Therapies like DBT and CBT allow for autistic people to communicate better and thrive, and researching autistic independence and bettering independence for autistic people is what we need to focus on as well. Getting rid of autism is a form of disabled genocide, and researching how to do so is being complacent and complicit in that process. Please listen to autistic people when they speak and keep the interest of the autistic community in mind.

Educational Needs and Teacher Workforce Training

Shawn Belt

On the autism spectrum more research should be done helping parents and educators in educating them as to how to effectively parent/educate their children. Outreach!! As the parent of a child (now adult) additional resources helping us to know to raise and navigate teh educational system would have been beneficial. Not only for children but young adults in higher education and for the higher functioning affected individuals... Even though we live in a very affluent area there are very limited resources which I could find for assistance. I can only imagine how difficult it must be for those less fortunate financially...

Sarah Carmany

Hello my name is Sarah Carmany I'm a strong self-advocacte and an Adult person who is dianosed with Autism Spectrum Disorder myself. I think one place to use the fund in autism research is in education. I myself went to school just like normal kid did. In other words I went throught young 5s and kindergarden just like other kids without disabilities do. In first grade I attend a program called title one which was part time special education to see if I needed special education services. Then in second grade I started to attend special eduacation. The school that I went to from young 5s all the way throught 12 grade was called Climax-Scotts Community schools which was in a rural community. I don't know if they still have the programs there now like I went throught back when I was there or not. I started going to climax scotts community schools in 1990-2004. 2004 was my graduating year that I walked with my class but I defurred my diploma to go to post secondary education which was in Kalamazoo called Youth Adult Program (YAP) throught Kalamazoo Regional Educational Service Agency(KRESA) I went to post secondary from the fall of 2004 until May of 2009 recieving my diploma from A highschool that I never attended due to me moving out of my parents house while attending the post secondary education. Going back to my grad school years from attending Climax Scotts Community Schools I had some of my classes in regular education and some in special education. Some of the classes that I had that were regular education was Math classes, Social Studies classes that taught American histroy, World geography class my sophmore year of highschool, English class general education I also took many different science classes, In my senior year of highschool I also took a regular education government class that at the time was required for me to pass. In my senior year of high school I nalso took a biology class that was regular education also. So just from my experience I would think so of the research funds should go towards eduction as well. Oh and by the way just to let you know throuhgt grade school I did receive many awards and certificated that includes honor roll certificated and back when they had the MEAP test I received a certificate in the writing test from the governor of Michigan at the time that I completed the MEAP test along with other awards from my youth. So may be education. Plus I didn't recieve the autsim spectrum diagnosis until I was an adult anyways. When I was 6 years old I was diagnosed with Attention Defict Disorder(ADD). Then when I was in junior high I was diagnosed with emotionally impaired. Then when I atended YAP which was the post secondary I was diagnosed with Autism Spectrum Disorder.

Trigger warning: The following comment contains reference to abuse and other sensitive topics.

Cody Fletcher

I wanted to suggest you consider bringing in legislation to give greater protections to people with Autism Spectrum Disorder by allowing children in schools diagnosed with autism to wear or carry a hidden recording device. Should you test out my suggestion with 1000 children of all age groups in public education, you'll find that 1000 recordings reveal the covert abuse that any child with disabilities is subjected to by neuro-typical aggressors who are children and staff members of the schools. Allowing covert abuse against children with ASD in schools negatively impacts every child, making it more difficult for them to become confident, whereby their propensity for success is diminished. If you truly want America to be one the world can be proud of, promote true protection and assimilation of children with disabilities to ensure a brighter future t for all.

Ebru Eser

There should be some focus in educating secondary school teachers on updated information on the autism spectrum. Elementary school teachers should be a primary focus, since children spend more time with them on a weekly basis. If "lecturers" do workshop sessions at schools every month or two months, they can teach school staff on how to help neurodivergent children in order to prevent enforced internalized ableism at a young age. So many teachers interact with many undiagnosed neurodivergent students, but oftentimes they dismiss their behavior as "shy; quiet" or "unruly; disruptive". Teachers should learn to recognize the diverse signs of an undiagnosed disorder and learning disability.

Tracey Stanislawski

Thank you for the opportunity to leave a comment and for your consideration of this topic for further research. My son is Autistic-high functioning, which led to a late diagnosis- he was 11 years old. He is my youngest of 4. We need to swiftly and drastically look at how our school systems are supporting our students with Autism. There should be no such thing as "Educational Autism". A child who is diagnosed with Autism is a child with Autism. It does not go away at school. My son had severe anxiety and depression as a result of school (as documented by a neuropsych report) yet we had to fight for 2 years for an IEP he had to literally fail everything before we could get him any help at all. Our teachers are poorly equipped to deal with any mental health issues and in fact, exacerbated my son's condition. They also do not understand Autism. He tests out as "average" yet has below-average communication skills, but does not qualify for any speech services. He will be transitioning out of high school next year and is nowhere near ready to hold a job, his social skills are like that of a middle schooler. Please create systems that understand and support our kids to help them from falling through the cracks.

Jennifer Brooks

My name is Jennifer Brooks. I would like to talk to you today about autism research. I think the IACC should tell the government to pay for autism research about education. All levels of education should be included from Kindergarten to college. I think this kind of research is important because for far too long schools have been allowed to get away with doing absolutely nothing to help children on the autism spectrum even though they know these children exist. It is not acceptable for our schools to ignore the

needs of students who are blind, deaf, LGBTQ or affected by learning disabilities, so why is it acceptable to ignore the needs of students with autism? My needs as an autistic student were completely ignored by all the schools I attended. This resulted in my making inappropriate career choices and a lifetime of struggle to maintain and secure employment to allow me become a productive taxpaying citizen. It also resulted in many mental health challenges. I know I am not the only autistic person who has had these experiences. Please help the next generation of autistic students by finding ways to incentivize schools to stop ignoring the needs of autistic students.
I think the IACC should listen to the voices of autistic people the most. The research I talked about is important to autistic people, and it might answer questions we have about our lives.
It could solve problems autistic people have, so we can live the lives we want. Please help autistic people by asking for more research about education.
Thank you for reading my comment.

Robin Bellinger

Get MA dept of education for all towns to xreate a xomprehesive prek-12 xore currixulm for social skills for all students to hVe to learn by classroom teachers amd appropriate older school teachers Asap.

Affordable or free social skill classes for all ages any child who needs it in EVERY town.

Mairead Keogan

As an autistic social worker, I notice not only in the social work field but in the mental health field in general, there is little training on autism in educational institutions and places of employment. Research into this area, and the benefits of training on autism, would be very beneficial for the autism community so their therapists, social workers, and doctors can be more educated about this population.

Addressing the Needs of Autistic Individuals with High Support Needs

Sharon Castellanos

I am writing as the mother of a 22 year old high needs, non-speaking autistic daughter, and probably have autism myself. I am also an Education Specialist working at Paradise High School in Callifornia with children with disabilities.

Age 22 is a significant year in the life of a disabled person - it is the age where public schools are no longer required to provide people with services and education. I have dreaded this year for many years and have planned as much as possible to make the transition from "school-age" to "adulthood" as smooth as possible. I imagined a worst-case scenario and planned accordingly.

The reality is so much worse than I ever could have imagined or planned for. My daughter is enrolled in California's Regional Center system and has gone through the Self-Determination process, for which she received what seems like a healthy budget for services.

I have had to reduce my working hours from full time teaching to working one day a week so that I can stay an employee in the district and hopefully go back to work full time at some point, but right now there is no one else to care for my daughter. I am a statistic of a highly needed worker pulled out of the workforce due to a gross lack of services.

As of this email, my daughter has no services at all, with the exception of a few hours of respite with a worker I had to find, vet and train myself. Her auditory sensitivities have gotten so much worse since she graduated - she now stays in her room all day, with the exception of going on a long drive every day - 1-2 hours.

What day programs that exist in our area have huge waiting lists, and they are not designed for people with autism. Environments that are not mindful to the needs ot autistic people lead to autistic meltdowns, after which they are labeled "difficult", with "problem behaviors", and even "aggressive". These labels are grossly inaccurate and reflect the dearth of knowledge by management and staff as to what autism actually is and what the needs of autistic people are.

Here are the services we are "supposed" to receive (what's in our budget).

- day program with one on one staff for transition
- local gym membership with one on one support/trainer
- "behavioral specialist" (which is so inappropriate for any autistic person but is the only thing available to problem solve/strategize with)
- One on one staff for art classes at local community college
- Independent Life Skills training in home

Here's what we actually have:

- 15 hours of respite per week (so that I can work one day a week)

Here's what we need:

- Day programs with openings that are designed with the needs of autistic people in mind
- Adaptive PE support services for people who specialize in autism and work with adults
- Autistic mentor support
- Community College resources for non-speaking autistics
- AAC services for adults, including AAC mentors
- Therapists that work with non-speaking autistics
- Psychiatrists that specialize in autistic adults
- Research geared toward improved outcomes for autistic adults
- Coverage for accommodations such as sedation for medical procedures

In response to this critical lack of services for disabled adults in our area, I have contacted:

- Our local regional center (Far Northern Regional Center of California)
- Office of Ombudsman overseeing the Self-Determination Program for California
- Our local State Assemblyman (James Gallagher)
- Our local State Senator (James Nielson)
- Our US representative (Doug LaMalfa, CA-01)

I received a lot of sympathetic responses, but not one of these offices had any actionable plans to improve the living situation for adults with disabilities living in California.

This is a public health crisis.

Emilie "Jenn" Brown

My son is soon to be 26. He is a complicated young man who it often feels like the world has forgotten. His needs are complicated by behaviors that require specialized care. We were unable to care for him successfully in the community and so he resides for now in a state institution in NJ. As his mom, it feels like failure. It is also nice to have a place where he is safe. He is not fulfilled as a human being but he is safe. We are working on a plan to get him out.

He was recently taken to the ER because he could not pass urine. The solution was to place a catheter and drain his bladder. This required him to be sedated, as he would have been combative. He had over a liter of urine in his bladder. He was then discharged. No explanation and no curiosity. His bladder filled up again as he waited for transport back to his state institution. He was clearly uncomfortable. The nurse begrudgingly scanned his bladder again to find he had another liter of urine. He was sedated, and his bladder was drained.

There was no explanation given, no care plan, and no concern.

His official diagnosis is Phelan McDermid syndrome which he was diagnosed with at 23. While this is considered genetic neither myself or my husband are carriers. It is considered De-Novo or new.

It is truly amazing the difference in care when he is treated by a doctor versed in Phelan McDermid. They dig deeper, ask more questions, and just in general care.

I don't want to cure my son. I want to help him poop, pee, and not be in pain all day, every day. I want the medical field to understand that people with autism that are either nonverbal or have intellectual disabilities matter. That they can treat the symptoms. That just because they have autism, they can also have other medical issues.

It should matter why he couldn't urinate. It should matter that he is chronically constipated. Miralax can not be the only solution - it is toxic. You don't fix something by covering it up or by adding ingredients that are toxic. Why is his digestive system not working? What dietary changes can be made to help?

Now that he has Phelan McDermid - it does matter. I have a team of doctors that I can tap into and ask these questions. Why did my son have to wait 23 years to get a team of doctors? That all talk to each other!! Why, when I say he has PMS (Phelan McDermid Syndrome), does he get Cadillac treatment versus the bums rush when we mention autism or intellectual disability?

My son has medical, psychiatric, metabolic, behavioral, intellectual, and developmental disabilities.

He can't share his experience of disability using words. He can share with his behaviors.

My ask is to have microarray DNA testing available via Medicaid nationwide. There have to be more people like my son without answers.

Can we make Medicaid portable? We are reaching retirement age and are not likely going to be able to retire in NJ. We have spent over $1 million out of pocket on my son we have little or no retirement money. We will not be able to take our son with us if we need to leave. We can't leave and we can't stay.

Can we look to treat the underlying symptoms? ABA, Floortime, etc etc etc are all great but without taking care of the inflammation, MTHFR, and other issues we are just using a garden hose to put out a 4-alarm fire.

Are there people on the IACC that understand people that require high support needs? People like my son? He can not qualify or quantify his experience of disability but he matters.

Thank you for the work that you do.

Brandon Becker

Thank you for the opportunity to comment on the update of the Interagency Autism Coordinating Committee ("IACC") Strategic Plan ("Plan").

It is crucial that the Plan focus on (1) advocating for funding necessary to maintain a robust system of community-based services, especially 1-to-1 supports for those individuals who cannot work in a community setting without 24x7 supports, (2) identifying solutions to the drastic shortage of direct support professionals available to provide such 24x7 supports and (3) working toward a sophisticated assessment of the full range of autistic needs as recommended by the National Council on Severe Autism ("NCSA") in its October 12, 2022 letter.

Further, the Plan must itself assess, address and respond to the needs of individuals across the spectrum, including (and perhaps especially) those with the most intensive needs and those who cannot speak for themselves. Indeed, as the NCSA noted in its letter, the Plan should not avoid language or recommendations that address those who have the most intensive needs. In this regard, when the Lancet Commission (2021) recommended recognizing a category of “profound autism” some viewed the words as “highly problematic.” Nevertheless, Professors Carman and Lord noted: “Our goal was to provide a term that could be used, if appropriate, to describe children or adults who need intensive support throughout their lives. The intended aim was to highlight the needs of this vulnerable and underserved group of autistic individuals.” Spectrum, Feb. 15, 2022.

More importantly, language that accurately describes a person’s needs is crucial to communicate about, and advocate for, the services necessary to meet those needs. Whatever specific words are used, however, the IACC must not avoid describing the specific needs of all people at all parts of the spectrum, especially those with the most intensive needs.

I hope the IACC will recognize the critical needs of those most in need. The voiceless. The self-abusers. The violent. The runners. You will do little good — and very much harm — if those most in need are made invisible. Thank you for your consideration.

Note: The comment below refers to death and other sensitive topics.

Eileen Nicole Simon, R.N., Ph.D.

DEATH IN A GROUP HOME

"Conrad is dead," my husband cried over the phone. "Please come home."

I had just arrived at work on the morning of January 17, 1995. The phone on my desk was ringing.

One of my co-workers drove me home. Another followed in her car.

My husband was home, and so was Conrad's brother Matthew. Matthew had been ready to go out the door, to work, when the phone rang. The call came from the medical examiner's office.

I called the medical examiner, and asked if I could come see Conrad.

"The remains have already been bagged," he told me.

Conrad was 31 years old. Cause of death was found to be chlorpromazine (Thorazine) intoxication.

The psychiatrist who prescribed 1500 mg/day of Thorazine (500 mg at 3:30pm, 7pm, and 8:30pm) should be serving a life sentence in prison.

She also prescribed Haldol 6 mg/day (3 mg at 8am and 3:30pm), Depakote 2000 mg/day (500 mg at 8am and 3:30pm), 1000mg at 7pm, and Chloral Hydrate 2 grams at 8:30pm.

Conrad never had a seizure disorder. Depakote was uncalled for. A fuller description can be found at conradsimon.org/Conrad.html#death.

I had been accused of being an abusive mother, and was not allowed to visit Conrad at his group home.

My husband told me to just stay away.

"They won't kill him," my husband told me. But they did.

Mental Health Research, Services, and Treatment

Elizabeth Bonnell

I think it’s really important to research methods for improving mental health outcomes for autistic people! Many autistic people have reported that they find traditional talk therapy unhelpful, because they have already spent years reflecting on what their therapists are asking them about. Others may not have the language to verbally respond, but desperately need support. My younger sibling struggles so much with ser mental health, but because se has trouble to finding the language to answer questions se are almost entirely unable to participate in treatment. Se really need treatment, but I don’t think the treatment se need exists yet. Starting to develop that treatment could help my sibling and many others around the globe!

Chelsea Sarring

Please prioritize research about treating anxiety in autistic people. It would be important to know exactly what sort of accommodations or therapies would be effective to ease the anxiety of autistic people at work or school (without forcing the autistic person appear neurotypical). In addition to anxiety, research in identifying and treating PTSD, cPTSD, and similar disorders in autistic people needs to be expanded. These types of research would allow autistic people to live more fulfilling lives.

Daniel Hardy

I am an autistic psychiatric nurse practitioner, married to an autistic teacher. We both work with autistic individuals in our chosen fields, as well as at home with our child. What we would like to have insight into is how to help with PDA (demand anxiety/demand avoidance) and research on how to close the gap between what autistic individuals, ourselves, seek as the goals of treatment (job satisfaction, independence) versus the traditional goals of treatment (mimicking neurotypical behaviors, socialization, responses.

Laura Contreras

These are people who have functioned their whole lives thinking there was something wrong with them because they never seemed to fit in with others. We struggled with relationships in every area of our lives, with coworkers, supervisors, friends, partners, even family without knowing why. We have sensory sensitivities that worsen our lives in many ways.. lights too bright, sounds too loud, fragrances way too fragrant, etc. We covered our confusion and uncoordination and disorganization by watching how others acted and trying to imitate. Many of us do such a good job our friends and family are shocked at our diagnosis. But masking left us not knowing who we really are as people and often in a state of depression and anxiety. I respectfully ask that you set aside new and/or increased funding for mental health counseling, legal assistance, inclusion programs, art, animal and nature therapy, and new subsidized housing voucher programs for older adults on the autism spectrum, as well as separate retirement communities for elderly autistic adults that cater to their specific needs. Thank you.

Employment

Lauren Agoratus

I listened with great interest to the Mathematica study. Would also like to submit an article on employment based on our national study by MPACT/RAISE (national Resources for Access, Independence, Self-Determination & Employment) https://reader.mediawiremobile.com/epmagazine/issues/208168/viewer?page=25

Steve Condrey

More emphasis needs to be placed on increasing autistic participation in the workforce. With an unemployment rate approaching 80%, the consequent lack of economic power hinders the ability of autistic adults to effectively self-advocate. Improving both job preparation for autistic people leaving the school system and awareness among hiring professionals and employers would improve this situation drastically. Employers are unaware of the accommodations that are available to integrate autistic adults into the workforce, including government assistance. And hiring practices are conducted with non-autistic workers in mind. The greatest advances towards improving the life experience of autistic adults can be made by bridging these gaps.

Josh Huffman

In recent times, a greater emphasis has been placed on ensuring employment for autistic people. Many companies are now putting extra emphasis on ensuring that their workforces are as friendly to neurodivergent people as possible. In a time where more than 80% of autistic people are unemployed or underemployed, this is crucial.

For this reason, it is important that the IACC consider investing more money into helping autistic people receive employment. The "Autism Cliff," in which many autistic services disappear after an autistic person becomes an adult, is a well-documented phenomenon that needs to finally be addressed, and helping autistic people to receive employment is an excellent place to start.

Steven Clark

I would like the IACC to conduct research on employment opportunities for autistic college graduates.

John Comegys

Speaking as a certified vocational rehabilitation counselor, past special ed teacher and as one on the Autism spectrum myself, there can be no greater need for research than to clarify any special abilities common to Autism, if any, and ways to accommodate these special abilities and concomitant disabilities as a way to increase the appallingly low employment rates among those on the autism spectrum, especially among the better educated.

The Role of the IACC and the Federal Government

Theodore Szpakowski

I think the IACC needs to include more autistic people. I also think that the IACC should prioritize giving funding to projects that include autistic researchers rather than those where all researchers are non-autistic.

Anthony Goleman

I think the U.S government needs to work on making services like medical care easier to access by autistic people. Autistic people are often treated like they don't know their own symptoms or turned away from things like gender transition services just because they're autistic

Alex Candeloro

My name is Alex Candeloro and I'm Autistic.

I would like to talk to you today about autism research.

I find the monopoly of Behavioral Therapy in early intervention with autistic people concerning. I think the IACC should tell the government to pay for autism research into the efficacy of Occupational Therapy in place of Behavioral Therapy in early intervention.

This would help autistic children learn new skills and be able to use those skills to adapt to their surroundings, regulate themselves, and complete daily activities (like brushing their teeth, showering, eating, ect.) rather than focusing on correcting behavior.

The IACC should be making sure to listen to autistic people as any research done or not done will affect us most directly.

Please help autistic people by asking for more research about Occupational Therapy as an early intervention.

Thank you for reading my comment.

Daron Williams

are

I currently serve on the Diversity Advisory Committee for the Washington State Department of Fish and Wildlife. As an Autistic adult, I've focused my work on the committee on helping WDFW be a welcoming and supportive place for neurodiverse staff.

While this work is ongoing one thing has really stood out to me. Any conversation about Autistic and neurodiverse people in general has to be led and directed by Autistic people.

As your work moves forward, please make sure that Autistic people are 1) a part of all conversations, and 2) are in the lead for these conversations.

That doesn't mean that parents of Autistic people or other family members can't or shouldn't be involved. They bring an important perspective. And it also doesn't mean that medical experts can't or shouldn't be involved. Their expertise can help inform the conversation.

But no one knows what Autistic people need more than Autistic people. We have to be front and center in all this work. Non-Autistic people can't be the lead in conversations about Autism if you actually want to help Autistic people.

I was disappointed to see that there are no Autistic people as Federal members of this committee. While there are some Autistic people as Public members they're the minority of the members. If you want your work to truly serve Autistic people we have to be the majority of the members of the IACC--both public and Federal members. This also means that an Autistic person should be the chair of the IACC.

There are Autistic adults with medical expertise and ones who are conducting research into Autism. And there is a large and diverse network of Autistic people who are also self-advocates. Reach out to these people and make the IACC actually represent Autistic people.

Please make sure that our voices are heard and that we lead this conversation.

Eileen Nicole Simon, R.N., Ph.D.

SUMMARIES OF WRITTEN COMMENTS

Comments submitted to the IACC deserve greater discussion.

I am grateful that comments are archived. But IACC committee members tend to make long-winded comments of their own that are not well focused on the ideas sent in by those of us who are mere members of the public.

This is unfair.

We only rarely are allowed 3 minutes to speak. And spoken comments also should be discussed at greater length.

Most important for me is that damage in the brain be taken into account.

Whether by genetic abnormalities or injury around the time of birth. How is the inability to learn language the outcome?

Summaries of submitted comments likewise should be expanded to clarify the ideas we members of the public are trying to get across.

Many of us have proposed research on particular brain structures. Names of these brain structures should appear in comment summaries.

Please allot more time for discussion of public comments.

Potential Causes of Autism

Eileen Nicole Simon, R.N., Ph.D.

Late Diagnosis?

Brain injury is the cause of autism - the kind of autism recognized in children who have trouble learning to speak. My first-born son suffered head injury during birth. The large scar under his right eye remains highly visible still. He is now 60 years old.

Speech therapists at Children's Hospital in Boston were successful in helping my son learn to speak. They used Lotto Cards, and my son learned to recognize the printed words on the cards! My son was two years old when he learned to read, and his use of language continued to improve.

My son continued to speak using phrase fragments until he was almost six years old. Thus he used the pronoun "you" to refer to himself.

Now, at age 60, he has outgrown his early autism diagnosis. He had largely outgrown this diagnosis by age 20. I have trouble believing that "autism" can go unrecognized until a person is in college.

The IACC must focus on causes of autism evident in early childhood.

Brainstem Injury?

Why isn't injury of the brain prominently included in The IACC Strategic Plan??? Injuries that might disrupt language development should be of greatest importance.

In 1962 Seymour S Kety reported highest blood flow in the inferior colliculi, in the brainstem auditory pathway (ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed).

The inferior colliculi are two pea-sized centers of the auditory pathway in the roof of the midbrain.

In 1969 William F Windle (Scientific American, October 1969) reported damage in the inferior colliculi caused by a brief period of asphyxia at birth, 6 to 8 minutes (weisenborn-boer.nl/Geboorte/Windle.pdf)

In 1975 I proposed the inferior colliculi as a possible site of injury in autism (Arch Gen Psychiatry 32:1439-46).

In 1981 Louis Sokoloff reported, “The inferior colliculus is clearly the most metabolically active structure in the brain” (J. Cerebral Blood Flow and Metabolism 1:7-36).

In tables compiled by many users of Sokoloff's method, the inferior colliculi are always listed as the most metabolically active site in the brain. And note, the auditory system is rarely the focus of research using Sokoloff's method.

The research of Kety and Sokoloff should be discussed by members of the IACC. Why are my comments on brain damage not worthy of more than brief mention in summaries of public comments submitted???

Brainstem Injury?

Kulesza and Lukose (2008 & 2011) reported abnormalities of the "olivary complex" in the auditory pathway of people diagnosed with autism in childhood. They undertook this investigation based on a case report (in 1996) by Rodier and Romano at the Rochester NY School of Medicine.

Dr. Romano had this patient's brain preserved after her death at age 21. The patient's mother was alcoholic. This suggests damage of brainstem pathways similar to that described by Wernicke in 1881.

Following are citations to the reports of superior olive malformation by, Kulesza and Lukose, and the report by Rodier et al.:

1. Kulesza RJ, Mangunay K (2008) Morphological features of the medial superior olive in autism. Brain Res. 1200:132-7.
2. Kulesza RJ Jr et al. (2011) Malformation of the human superior olive in autistic spectrum disorders. Brain Res. 1367:360-71.
3. Lukose R, et al. (2011) Malformation of the superior olivary complex in an animal model of autism. Brain Res. 1398:102-12.
4. Rodier PM et al. (1996) Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. J Comp Neurol. 370:247-61.

Inferior Colliculus?

Malformation of the superior olive in the auditory pathway was reported in the brain from an autistic woman by PM Rodier et al. in 1996. RJ Kulesza and R Lukose discovered similar brain abnormalities in brains they examined from autistic people.

Dr. Kulesza replied to my inquiry about the inferior colliculus. He told me they had only asked for brain-bank sections from the superior olives.

Kulesza et al. have published more reports from 2019 to 2022 that the inferior colliculi and other brainstem auditory centers are injured in laboratory rats exposed to Depakote (valproic acid) during gestation.

Autism has been reported in many cases of prenatal exposure to Depakote, taken during pregnancy to prevent epileptic seizures.

Please lookup the ongoing research of R Kulesza. See, for example, McCullagh EA et al. (2020).

1. Rodier PM et al. (1996) Embryological origin for autism: developmental anomalies of the cranial nerve motor nuclei. J Comp Neurol. 370:247-61.
2. Smith A, et al. (2019) Structural and Functional Aberrations of the Auditory Brainstem in Autism Spectrum Disorder. J Am Osteopath Assoc. 119:41-50.
3. Mansour Y et al. (2019) Auditory Midbrain Hypoplasia and Dysmorphology after Prenatal Valproic Acid Exposure. Neuroscience. 396:79-93.
4. McCullagh EA et al. (2020) Mechanisms underlying auditory processing deficits in Fragile X syndrome. FASEB J. 2020 34:3501-3518.

Parrish Hirasaki

The pandemic caused an interruption in prenatal care that has produced a population of babies who were not scanned with ultrasound early in gestation. This creates an opportunity to conduct an epidemiological study of fetal ultrasound, the major change in prenatal care in the 2000s.

The increase in the prenatal exposure to ultrasound per pregnancy and the increase in ASD follow similar curves. The vibration and heating created during scanning seem a poor environment for the migration of brain cells which occurs during the first 20 weeks of gestation.

The FDA's regulatory designee American Institute of Ultrasound in Medicine (AIUM) formally states on its website that no epidemiological study has been conducted since the allowable intensity was increased (8-fold) in 1992. AIUM scientists have long cited the lack of a population of children who were not scanned as the reason but continue to dodge the topic now that such a population exists.

In 2012, Caroline Rodgers made a presentation titled? The Elephant in the Room? to IACC asking for prenatal ultrasound to be studied. So for over 10 years no steps have been taken by IACC to promote the examination of the impact of prenatal scans, the single biggest change in prenatal care in decades.

IACC should request that NIH establish a research grant for an epidemiological study that will build a database of children born in 2020 and 2021 who were not exposed to ultrasound during the first 20 weeks of gestation and will compare their health outcomes with children who were exposed. If there are no differences, this elephant in the room will be eliminated. But if it is the cause, the epidemic can be stopped with ease.

Increase Autism Acceptance and Reduce Stigma

Tracey Stanislawski

Thank you for taking my comment. I have a son with high-functioning autism. He was not diagnosed until he was 10. Prior to that and even now, he struggled in school. He struggles because of his "invisible" disability. We really need to work hard with all schools to rethink the way we perceive behaviors. There is a lot of money for schools now with mental health grants, however, all the money in the world cannot change people's attitudes about behavior. I understand that behaviors can be challenging in a classroom, but if we can get all staff (anyone who interacts with kids during the day- and including coaches) to understand -in the words of Ross Greene "They are having a hard time not giving you a hard time" it would go a long way in changing peoples perceptions and perhaps the trajectory of our children's (and then adults) journey in life. Thank you.

Chris Cottrell

I am autistic with what's known as "high functioning" or "low support needs" autism. This is because I can, with some significant effort and personal psychological expense, make sure people without autism are not burdened or disturbed. It is repeatedly shown that people without this ability to communicate on non-autistic terms can thrive when the right supports are in place. Instead of focusing on prevention, I posit the idea that IACC focus resources on support systems that aid autistic people who might be nonverbal in communicating with non-autistic people and to focus resources on an education campaign that destigmatizes autism.

Emma Peacock

There needs to be more research about how to change public opinion about autistic people, since many non autistic people still believe in autistic stereotypes that are harmful for autistic people.

Deanna Durben

I am an autistic person and a psychology major, and I think we should study things that improve autistic people’s quality of life and not ways to make us fit in better and mask.

We should study the emotional dysregulation and alexithymia that often occurs with ASD, as well as sensory sensitivities and overstimulation.

Inclusion of Underrepresented Groups

Beth Carey

I would like to recommend more focus, resources, and support be given to people who identify as female and are adults with Autism. My understanding is that not only are females significantly underrepresented in resources and support but adults in general seem to have more difficulty being properly identified and supported as well so the combination makes adult females a significantly underrepresented population. Much of the research has been skewed with heavily male participation thus making it even harder for females to be properly identified and diagnosed. This influences the number of skill professionals that can accurately give the correct type of support adult females need. In addition, in my lived experience, moms I know are realizing it more when their kids are being diagnosed rather than a doctor or other professional noticing it. I would love to see more supports for parents that have Autism because it is a unique challenge to be a parent and manage your sensory needs while raising a child and working. My final suggestion is more focus on PTSD and Autism. Studies show that people with Autism tend to experience more adverse life experiences and are more susceptible to PTSD because of that but I'd like to see more research on PTSD techniques specifically for people with Autism and PTSD vs. Nurotypical peers. Thank you for considering adults with Autism as you begin to make decisions.

Merideth Hartsell-Cooper

Please research ways to identify women, nonbinary & trans teens and adults with autism so that we can understand our needs and strengths. Include people of color and people with intellectual disabilities. Please include linguistically diverse individuals, including those who use assistive/alternative communication. Please research better ways to include and support us in our communities, homes, and schools. Please stop trying to cure or fix us. Please research the needs of pregnant autistic women & how to support us.

River Bradley

I am an autistic nonbinary person. I would love to see more research to develop more accurate diagnostic tools, to study how gender interacts with autism, tools to help autistic adults who got diagnosed late in life, interactions between autism and medical concerns such as thyroid issues, reproductive health, digestive issues, and sleep disturbance. Also I would love to see more on how ADHD relates to autism. Thank you.

Sara Ackermann

It should a lot easier for an adult to get tested. There needs to be way more research and such that included women and girls too, so we can stop being misdiagnosed all the time.

Nicole Lewis

We need more women, BIPOC, and adults in general included in studies. They haven't been researched enough.

Communication and AAC

Eileen Nicole Simon, R.N., Ph.D.

Syllable Boundaries?

Failure of language development is the most disturbing concern of parents who seek help for a child. Autism is often the diagnosis. Difficulty learning to speak is not a sign that is ever missed.

Language is the defining feature of the human species.

Social development cannot advance far without language.

William Windle (Scientific American, October 1969) described damage in the auditory pathway of monkeys subjected to asphyxia at birth. This damage occurred after only 6 to 8 minutes of oxygen deprivation.

Our son had to be resuscitated after birth. Then he suffered severe jaundice during his first week of life. He began to speak near the end of his first year. Our relief was short-lived. His nursery school teacher suggested he be evaluated by a psychiatrist. Autism was the diagnosis he was given shortly before his third birthday.

His speech was clear with good articulation, but he used the pronoun "you" instead of "I" or "me."

Roger Brown (A First Language, 1973) evaluated our son, and pointed out that he did not recognize syllable boundaries. Should speech therapy focus on syllable detection?

Tony Sandy

A few more observations from the other side of autism

When it comes to the symptoms of Aspergers disease, one area stands out above all others and that is communication. Taking things other people say literally for instance, coupled with not lying, even if it upsets others is because we give honest communication and expect it in return, even if we don't get it (mirroring). We are the little boy, who tells The Emperor that he is naked, not that he is wearing new clothes (not diplomatic).

Selective mutism occurs because we are not sure how to speak to outsiders (non family members). This also ties in with avoiding looking other people directly in the eye, so we don't engage with them, if we don't want to or staring straight at them, to give the impression we are 'normal,' which usually freaks them out more.

Wanting to 'fit in' can lead to over-rehearsed speech in our heads, which sounds cold and robotic. It can also lead to complex speech patterns (long winded / abstruse), aimed at impressing others. We can also miss emotional 'in your face' responses by others because social cues are missed. We can also jump in and interrupt conversations because we think what we have to say can't wait.

The autistic don't know how to speak properly, that is use verbal tools, so fail to moderate volume, tone, rate (speed) or rhythm: Think of setting up setting up amplifiers at a rock concert as well as coordinating a full orchestra or even tuning an individual instrument, in this case the human voice.

We are generally hypersensitive to reality but not always responsive to it: loud noise, bright lights, strong tastes and smells or rough / strange feeling textures can freak us out. Strong concentration may create the illusion that we are insensitive to pain, heat or cold etc but this is not the case, just that we ignore these conditions in our pursuit of our goals, becoming trance-like in such engagements of our attention (only our goals exist, not the outside world).

This severance from reality can lead to clumsiness as in me continually breaking glasses, when washing up (King Alfred burning the cakes because his attention was elsewhere).

We hate being hugged, getting patted on the head as adults do to children or people bumping into us and generally crowding our space, however we can do the same to others when we get caught up in the moment and forget they exist in turn.

Our obsessive interests can lead to self isolation, with little or no interaction with others (home loving / indifference to socialising). Like monks we cut ourselves off from the rest of the world, so that we can concentrate whole heartedly on the task in hand, with as little interruption and disruption to our routines and pursuits as possible (stable environment).

In my case this shows up in world war two tanks, the Daleks, Welsh castles (an English man's castle is his home), filling plastic eggs as a hobby and circling things in the TV guide I want to watch the following week. All these show the urge to contain or hold in / shut out outside influences or interference (defensive barriers or control points as exist within the body, a country's borders or creatures like insects and crabs that have an external skeleton).

I also create collages (mixtures of words and images) plus take photographs with my phone camera, which shows the visual orientation Temple Grandin, the autistic personality, talks about continually in her books and lectures. I have also created a series of books, eight in total, taking English apart and reconstructing it to display its patterns, in columns, which shows my obsession with language and another of our common traits (communication again and understanding words and phrases).

As we are 'Strangers in a strange land' as The Bible puts it, we have a terror of getting things wrong and standing out as outsiders (being ostracised, when we don't choose it). We blunder anyway, so this is not entirely unexpected as a result but like 'Zelig' in Woody Allen's film of the same name, we do our best to imitate those around us and fit in.

We are not compatible with the school system because we don't know how to behave and it doesn't stretch us (I hated it but fitted in better than many in my position, except when it came to maths. A certain teacher aimed questions at me, in front of the whole class, deliberately to humiliate me as he knew I couldn't answer them).

We are non conformist, not because we deliberately want to rebel against authority but because we don't have the social skills to fit in (we are size ten feet in size five shoes as I once put it). Our rebellions (temper tantrums) are because of sensory overload. Like a bucking bronco we kick off unwanted pressure and distractions from outside. For instance when I was a volunteer at The Dunn Nutrition Centre in Cambridge, I lost my temper because my room was beside the toilet block and I got fed up with banging doors and toilet seats. I locked the entrance into it and threw the keys in the courtyard, leaving shortly after that.

Digestive sensitivity (histamine reaction to wheat and food additives), disclosed themselves through indigestion, hay fever and twenty odd years of migraines. It may also be why I have to continually crack joints in my body (not only knuckles but knees, wrists, neck, lower back, between the shoulder blades, ankles and for some odd reason my left big toe but not my right). I also have restless leg syndrome, which is probably an offshoot of this. I also flick, tap and raise individual fingers, which I assume is my form of ticking but not like a clock.

If we think in pictures, then by inference we not only look for subject matter but comparisons to find matches. It may be that our minds work like face recognition software or finger printing. In other words this is our association software, not words and spelling.

Parent/Caregiver Support Needs

Steph Herold

Many autistic people go on to have autistic or otherwise neurodiverse kids. In fact, many parents don't discover their own neurodivergence until a concern is raised about their child. More research is needed to understand how to support autistic parents.

Erin Garcia

Having a list of developmental milestones and/or variation of autistic pediatric milestones would be profoundly helpful for parents who receive their child’s diagnosis. Milestones shared without judgement will also prevent parents from fearing a diagnosis and empower them to support and affirm their autistic child as they grow. For example sharing Gestalt language processing milestones as compared to the typical language development that is often considered the “standard”.
Thank you for the work you do!

Language Regarding Autism

Joseph, Joe, and Michele Atkinson

The following public comment by the National Council on Severe Autism in October 2022 was resubmitted by this commenter: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public_comments.pdf?ver=5

Michael Baron

For what it is worth I am the sole survivor of the group of parents who founded what is now in the UK the National Autistic Society in May 1962.

So I am pretty old but puzzled now that what was new and exciting once is no longer - we changed from Psychotic to Autistic under the persuasive influence ,intellectually, of Lorna Wing in October or November of that year. After 60 years is it not time for a change of name ,change of diagnosis and prognosis ? There is no leadership from the UK so why not you ?

My son is now aged 65 and I talked one sidedly to him on Sunday, He lives in an excellent care home but is utterly dependent on others to look after him. How he has the same diagnosis -autism - as someone like a TV star or an actress is more and more a mystery to me and I wonder what madness I dreamed up in my idealistic time since I was the first chairman of what is now the UK NAS. Every one of any worth knows the name is no longer right .

So change it please to something more neuro diverse.

Justin Acta

I am a person diagnosed and living with Autism. I write to implore you not to buy into lobbying by organizations advocating for people with severe autism. These groups have tried to exclude higher functioning autistic individuals and those with a less severe symptoms from falling under the autism spectrum diagnosis. These groups want to narrow the understanding of Autism as an not including those with the most severe characteristics and behaviors. They want o exclude people like me who depend on services but have moderate symptoms.

Please do not narrow your understanding of autism and there is nothing wrong with neutral language.

Jillian Rhoades

I believe it’s great to see the strengths in all groups of people, but not at the cost of minimizing the voices of the smaller (but growing) minority who require the most care (who are silenced due to lack of verbal ability). Our wording needs to balance the reality of providing hope to individuals and families while also acknowledging the suffering that many individuals and their families experience with Autism. There are families who are floundering without adequate services and support and presenting Autism in a way that indicates that it’s just another identity to embrace is not telling the full story and it leaves those families who require the most support to face harsh criticism when speaking their truth, and it will result in fewer services being available to those families.