

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network, in light of the recent 2019 reintroduction of the Autism CARES Act¹ and its annual commemoration of Autism Acceptance Month,² reiterates its commitment to autism research that enhances the self-determination of autistic people and our community integration. ASAN advocates for a vision of the world where not only is the broader community “aware” of the existence of autistic people, but where our value as human beings is celebrated and we have access to the resources and accommodations we need. Research *on* these resources and accommodations, however, remains woefully limited.

According to the 2016 IACC Portfolio Analysis Report, which contains the latest data available, only a meager 2 to 3% of all federal autism research funding in 2016 went to research on improving services and supports. Although the IACC reports 6% of total autism research funding went to services and supports (research which falls under the 2016-2017 Strategic Plan’s Question 5, “What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?”), *more than half of that funding* went toward the “practitioner training” subcategory. Funding for practitioner training, even if it is primarily focused on increasing the cultural competency of practitioners,³ is not funding for research that enhances the quality and diversity of the services available to us. We call on the IACC to end the use of this “creative accounting”⁴ and honestly report— and meet— the need for more research on services and supports.

Even though autism is a lifelong state of being, there is still far too little research funded that addresses how autistic people grow and develop across our lifespans. Only 2% of all autism research funding goes to lifespan-related issues, and 74% of this extremely limited funding goes specifically towards research on transition to adulthood. Only 6% of lifespan issue funding addresses research that would address our quality of life and ameliorate

¹ Autism CARES Act of 2019, H.R. 1058, S. 427, 116th Cong. (2019).

² Autistic Self Advocacy Network, *Autism Acceptance Month: Acceptance is An Action*, <https://www.autismacceptancemonth.com/> (last visited April 5, 2019).

³ The IACC notes that this is the primary focus of the practitioner training subcategory on pg. 52 of the 2016 Portfolio Analysis Report, stating that the supports and services subcategory includes “research to develop and evaluate the training of service providers who work with individuals with ASD, *particularly identifying culturally appropriate best practices*” (emphasis added).

⁴ Autistic Self Advocacy Network, *ACTION ALERT: Tell HHS to Stop “Creative Accounting” with Autism Research*, July 10, 2012, <https://autisticadvocacy.org/2012/07/action-alert-tell-hhs-to-stop-creative-accounting-with-autism-research/>.

negative impacts of co-occurring conditions. While transition to adulthood is undoubtedly important, excessively focusing funding on only this phase of life means that other issues - such as aging in autistic people and the trajectory of autistic adulthood more generally - are left underfunded and under-researched.

The main focus of autism research funding unfortunately continues to be on the biology and causation of autism and on the elimination of autistic traits. In 2016, *more than \$127 million* — nearly a third of total funding — was spent solely on research on the biology of autism. \$86 million was spent on research on “risk factors” for autism and the “disabling aspects” of ASD. By contrast, total funding for research into lifespan issues in autism amounted to only slightly more than \$9 million. The continued disproportionate funding of research that does not serve the needs of the autistic community, and systematic underfunding of research central to our quality of life, is unacceptable.

ASAN strongly urges the IACC to advise the federal government - particularly the National Institutes of Health, which funds 64.3% of all autism research- to invest in research that supports and benefits autistic people ourselves rather than research that attempts to prevent our existence. It is far past time for the IACC, which has verbally expressed interest in supporting a better future for our community, to back up its statements with concrete, actionable steps to make that future a reality.

ASAN’s further comments on specific issues of interest are detailed below.

Gender and Sex Disparities in Autistic People

ASAN appreciates the IACC’s strong interest in research on the needs of autistic women and girls, as expressed by its Cross-Cutting Objective in the 2016-2017 Strategic Plan and its support of research addressing that objective in the 2016 Portfolio Analysis. IACC’s 2017 Summary of Advances, for example, contains a research study which attempted to determine the ratio of autistic boys to girls and noted that “girls with ASD are more likely to be overlooked, misdiagnosed, or identified late.”⁵ Prioritizing research into the services and supports that will help autistic girls and women thrive is critical.

⁵ R. Loomes, L. Hull, W.P.L. Mandy, “What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis,” 56 *J. Am. Academy of Child & Adolescent Psychiatry* 466, 466-474 (June 2017).

However, in its 2016 Portfolio Analysis, the IACC's Cross-Cutting Objective for Question 2, relating to the biology of autism, was "to understand the biological basis of sex differences in ASD, such as differences in brain structure and functioning among girls and boys." This objective assumes that such differences exist and that they exist due to genetic or biological causes, rather than differences in how men and women are raised. Yet the evidence base for these assumptions is weak--and, by and large, there is not consensus that neurological sex differences in non-autistic people have genetic or biological causes. The IACC should expect the same level of basic rigor from research focusing on autistic people. We recommend that the IACC focus on research similar to that which was proposed (but notably not funded) in IACC Question 6, which would examine gender in autistic adults and how it impacts our health and our lives.

Furthermore, the IACC continues to omit any mention of the high number of gender nonconforming, gender non-binary, and trans autistic people in our community, nor does it describe the need for research which specifically addresses the needs of this population. The omission grows ever more troubling in light of the increasing number of research studies finding that autistic people are more likely to be LGBTQ⁶ and struggle with finding support⁷ for our sexual orientations and gender identities. We urge the IACC to better support and advocate for LGBTQ autistic people.

Racial and Socioeconomic Disparities in Autistic People

Although we appreciate the addition of an article on racial and ethnic disparities in the 2017 Summary of Advances, more research must be done that addresses the underdiagnoses of autistic people of color, low-income autistic people, and autistic people who speak English as a second language. According to the Autism and Developmental Disabilities Monitoring Network's 2018 report, white children were 1.5 times more likely to be diagnosed with ASD than Black children, and 1.2 times more likely to be diagnosed with ASD than Hispanic children. Black children were 1.5 more likely to be diagnosed with ASD than Hispanic

⁶ R. George and M.A. Stokes, "Sexual Orientation in Autism Spectrum Disorder," 11 *Autism Research* 133, 133-141 (2018).

⁷ John Strang, "Why we need to respect sexual orientation, gender diversity in autism," *Spectrum News*, (November 27, 2018), <https://www.spectrumnews.org/opinion/viewpoint/need-respect-sexual-orientation-gender-diversity-autism/>; Evan Urquhart, "A Disproportionate Number of Autistic Youth Are Transgender. Why?" *Slate* (March 27, 2018, 1:33 PM), <https://slate.com/human-interest/2018/03/why-are-a-disproportionate-number-of-autistic-youth-transgender.html>.

children.⁸ While the report states that the disparities are smaller than they were in previous years, they nonetheless continue to exist. Ensuring that practitioner training is culturally competent is simply not enough to ensure that autistic people of color receive the support they need to thrive.

ASAN particularly encourages the IACC to advocate for research which examines differences in long-term outcomes (for example the percentage of people who successfully obtain competitive integrated employment) between white autistic people and autistic people of color. ASAN also advises the IACC to encourage investigation into systemic inequities which have a significant, known negative impact specifically on the health and well-being of autistic children of color, such as the disproportionate application of school discipline.

Access to Communication

Access to communication is a vital human right. Autistic people may use a wide variety of possible forms of communication, including verbal communication, behavior as communication, and augmentative and assistive communication (AAC) devices. ASAN reviewed the Autism Research Database after it was updated with data from 2016 and found that research listed under Research Question 4, “Which Treatments and Interventions Will Help?” did contain important studies which examined the effectiveness of various forms of augmentative and alternative communication (AAC) for autistic people, mostly children. AAC-related studies were generally outnumbered by those which attempted to teach non-speaking autistic children how to speak or to improve the expressiveness of the speech of those with inconsistent speech. ASAN encourages the IACC to prioritize research into AAC and into the development of other forms of alternative communication in both children and adults.

ASAN, in partnership with a number of national disability rights organizations, cautions the IACC against claims that any particular form of communication is not “evidence-based,” such as those made by the American Speech and Hearing Association (ASHA) with respect to Rapid Prompting Method (RPM) and Facilitated Communication (FC).⁹ The effectiveness of a communication support for a specific autistic person should be determined on an individualized basis. More research is needed to establish which methods work best for

⁸ Autism and Developmental Disabilities Monitoring Network, *Community Report on Autism 2018: A Snapshot of Autism Spectrum Disorder among 8-year-old Children in Multiple Communities across the United States in 2014*. Washington, D.C.: Centers for Disease Control and Prevention, 13-14.

⁹ Autistic Self Advocacy Network, *ASAN Response To ASHA Position Statements*, August 27, 2018, <https://autisticadvocacy.org/2018/08/asan-response-to-asha-position-statements/>.



Nothing about us without us!

which autistic people, and how to best support every autistic person to access communication.

Working with the Autistic Community

Meaningful advances in the scientific understanding of autism, in the knowledge of how autistic people grow and change across our lifespans, and on which services and supports best serve autistic adults, will not and cannot happen without the participation, input, and leadership of autistic people. ASAN continues to advocate for greater representation of autistic people on the IACC itself, including non-speaking autistic people and autistic people with a range of ethnicities, lived experiences, and support needs. ASAN supports robust partnerships between the research community and the autistic community, especially with respect to grant reviews, increasing the numbers of autistic researchers, and increasing the participation of autistic adults in research at all stages. ASAN urges the IACC to reach out to large federal funders of autism research (such as the National Institutes of Health) and request that they: (1) research autistic adults as well as children; (2) invite a diverse cohort of autistic adults to act as participants in autism research; and (3) consult with us specifically rather than only our parents or caregivers.

ASAN appreciates the opportunity to provide comments on the IACC's priorities and the future of autism research. For more information on our comments, please contact Julia Bascom, Executive Director of ASAN, at jbascom@autisticadvocacy.org.