



July 2nd, 2021

Thank you for the opportunity to submit written comments. The Autistic Self Advocacy Network (ASAN) is pleased that, after an absence of 2020 meetings due to the coronavirus pandemic, the Interagency Autism Coordinating Committee (IACC) will resume its efforts to ensure that funding for autism research is properly allocated. New meetings for the IACC represent an opportunity for the committee to further commit to the values articulated in its 2018-2019 Strategic Plan, namely to “accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan.”¹

In particular, the reconvening of the IACC represents an important opportunity to reform the federal government’s autism research *priorities*. The priorities of the federal government set a standard for the direction that privately funded research should take. Research into intellectual and developmental disabilities (IDD) - particularly research on the supports and services that best enhance living, learning and working in our communities - has the potential to improve the lives of millions. Nonetheless, autism research in the past has been excessively focused on the cause and prevention of autism, as well as medications and coercive therapies designed to make the autistic person appear less autistic. The IACC’s 2021 meetings could, instead, pave the way to a better future for *all* autistic people.

The Autistic Self Advocacy Network (ASAN), a 501(c)(3) nonprofit advocacy organization created by and for autistic people ourselves, shares the IACC’s commitment to better autism research. ASAN’s primary goal is and has always been to ensure that research funding is directed towards high-quality research with the highest potential to directly benefit autistic people. ASAN has commented on many of the IACC’s full committee meetings in the past in order to provide the committee with input on the values and interests of the autistic community as a whole. ASAN’s comments on the current meeting are below.

¹ Interagency Autism Coordinating Committee Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder (ASD): 2018-2019 Update at IV (Jul. 2020), *available at*: https://iacc.hhs.gov/publications/strategic-plan/2019/strategic_plan_2019.pdf?version=3.

Directing Autism Research Towards the Priorities of Autistic People

ASAN supports research and workshops included in the IACC's 2018-2019 Strategic Plan that address important priorities of the autistic community. The Strategic Plan included a comprehensive September 2018 workshop on the co-occurring disabilities most common in autistic people (for example sleep, epilepsy, and gastrointestinal and connective tissue disorders). It additionally included a 2019 workshop on mental health in autistic people, a subject sorely in need of attention from the research community. These workshops examined the trajectory and impact of these conditions across the lifespan - a significant improvement upon prior work in this area - and included the perspectives of autistic people ourselves. Several of the workshops, projects, and studies described in the Strategic Plan either interviewed or worked directly with autistic adults. Our inclusion and investment in autism research is critical for ensuring that future research aids autistic people. ASAN also appreciates that the IACC's 2019 Summary of Advances includes research on important under-researched topics, such as the impact of home and community-based services (HCBS) waivers on racial disparities in service needs and the lack of adults with intellectual disabilities included in many ASD-related research studies.²

Nonetheless, there is a significant gap between the IACC's publicly stated *commitment* to autism research focusing on the real needs of autistic people and the funding actually directed towards this work. According to the 2017-2018 IACC Portfolio Analysis Report,³ which summarizes federal and private funding directed towards autism research, as of 2018 a mere 3% of total autism research funding went to research on the quality of services and supports. Although the 2017-2018 report again states that 6% of autism research funding went to services and reports (research which falls under the Strategic Plan's Question 5, "What Kinds of Services and Supports Are Needed to Maximize Quality of Life for people on the autism spectrum?"), *nearly half of that limited funding in 2018 -46% -* went to the "practitioner training" subcategory. Practitioner training is *not* research on which services and supports work best for the diverse needs of autistic people - which is research our community urgently needs.

Research Question 6, the only question to focus specifically and exclusively on lifespan issues ("How Can We Meet the Needs of People with ASD as They Progress into and Through Adulthood?") is similarly underfunded. Funding directed towards Research

² Interagency Autism Coordinating Committee, 2019 Summary of Advances in Autism Spectrum Disorder Research 28, 38 (May 2020), available at: https://iacc.hhs.gov/publications/summary-of-advances/2019/summary_of_advances_2019.pdf.

³ Interagency Autism Coordinating Committee, 2017-2018 Autism Spectrum Disorder Research Portfolio Analysis Report (Apr. 2021), available at: https://iacc.hhs.gov/publications/portfolio-analysis/2018/portfolio_analysis_2018.pdf?ver=2.

Question 6 accounted for only 3% of all funding for autism research. Additionally, a full 39% of this funding went towards research into only one age group and type of lifespan issue: effective transition services for young adults and adolescents with disabilities.⁴ While ASAN agrees that the transition into adulthood is a critical period, funding imbalances shortchange other critical lifespan research. Autistic people undergo the same range of life events as non-autistic people and spend the majority of our lives as adults. Our needs in mid-life, our experiences with marriage and parenthood, the ways our health and disability might change as we age, and our experiences with aging itself deserve serious consideration, research, and support.

ASAN recommends that the IACC prioritize the use of longitudinal aging-related studies of autistic people of a wide variety of backgrounds, socioeconomic statuses, genders, and ethnicities. In particular, ASAN emphasizes the need to ensure racial, ethnic, and gender diversity in future autism research. As a study in the IACC's 2019 Summary of Advances notes, Black, Indigenous, People of Color (BIPOC) individuals are historically under-identified as autistic people, and there are often disparities in the services that they receive. Any study which includes autistic adults but fails to include BIPOC people will dramatically reduce its efficacy to the autistic community.

Critical research largely remains underfunded in large part due to an excessive and often ethically questionable focus in the autism research community on the biology and causation of autism. The IACC research questions which represent research on these two topics (IACC Question 2 and Question 3) together accounted for more than half of all research funding in 2018 - 61%. While some issues important to the wellbeing of autistic people, such as epilepsy and other co-occurring physical and mental health conditions, require traditional biomedical research, the overwhelming majority of the research represented by these two questions transparently aims to identify and modify the biological mechanisms underlying autism in order to ultimately reduce the number of autistic people in the world. ASAN, and the autistic community as a whole, strongly opposes such research. ASAN urges the IACC to utilize its first committee meeting in more than a year to lead a change in focus for autism research; from research that aims to eliminate us, to research that aims to help us live good lives.

Avoiding an ASD Diagnostic “Research Silo”

Autistic people have a great deal in common with other people with intellectual and developmental disabilities (IDD). We tend to experience many of the many of the same academic and social differences, many of the same executive functioning impairments,

⁴ *Id.*

many of the same lifelong support needs, many of the same issues finding and securing employment as adults, and a similar array of co-occurring disabilities. While there are some research priorities and concerns that may be specific to autistic people (ex. our high suicide risk), these are rarer than concerns that are common to all people with IDD.

Nonetheless, historically many of the researchers, agencies, and educational institutions which develop effective services and supports for people with IDD have few connections with siloed autism-specific research and do not receive autism research funding. The workshops and presentations listed in the 2018-2019 Strategic Plan indicate that this discrepancy still exists. For example, the September 2018 co-occurring disabilities workshop and the May 2019 mental health workshop do not reference research in these areas performed on people with other developmental disabilities, or generalist research on all people with IDD in these areas, even though this research exists and should inform research on autistic people. Similarly, the 2019 Housing Working Group largely ignored decades of research and practice showing the efficacy of community living for all people with intellectual and developmental disabilities, including those with the most significant support needs. ASAN recommends that the IACC discuss situations in which autism research could be better informed and improved in quality by consulting with the agencies, educational institutions, and researchers working on research on people with IDD generally and other groups of individuals with IDD. Autistic people are not served by research that reinvents the wheel or that views us as a separate category entirely, rather than a subset of a common group of people with disabilities.

Inclusion of Autistic Adults in Autism Research

While some researchers have begun partnering directly with autistic people ourselves in the design, production, and analysis of their research, most autism research is still “about us, without us.” ASAN recommends that the IACC use its unique role to promote the inclusion of autistic adults ourselves in *all* forms of autism research. Autistic adults can provide input on not just our co-occurring disabilities and lifespan issues, but on communication access, the design of studies on the neurology of autism, studies on which services and supports work best for different groups, and indeed on any aspect of autism research.

We particularly encourage the IACC to recommend the use of community-based participatory research which works directly with autistic self-advocates ourselves (including non-speaking self-advocates and self-advocates with intellectual disabilities), rather than acquiring study participants solely by contacting parent representatives or our service providers. We possess firsthand knowledge and experience of our own bodies and minds that other stakeholders lack. High-quality research done in partnership with autistic adults ourselves is the only way to reduce gaps in the knowledge base.

Communication Access

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. At least one-third of autistic people are not able to rely on speech to communicate. Nonetheless, much of the current research *on* communication and autism largely does not reflect the diversity of communication styles in autistic people. Instead, it tries to determine how to get us to communicate through speech.

ASAN is concerned about the excessive focus on only verbal speech reflected in the IACC's Autism Research Database entries for 2018, the latest year available.⁵ While there were nearly 13 pages of research which examined the impact of autism on verbal language and the best means of facilitating its development in autistic people, there were only a few entries on the best ways of facilitating the development of AAC use or other alternatives to verbal speech. ASAN therefore recommends that the IACC prioritize significant additional research into how autistic people may best establish other forms of effective communication. This research has immense potential to profoundly impact the quality of life of autistic people who do not currently have access to a robust method of communication. More research is urgently needed to establish which methods work best for which autistic people, and how to best support every autistic person to access communication. Communication is a human right, and Nonspeaking autistic people deserve research that prioritizes their needs and interests.

ASAN again thanks the IACC for the opportunity to comment. We hope that the IACC is able to put forth new frontiers for autism research, rather than retreading upon the old. For more information on ASAN's positions with respect to autism research, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.

⁵ *IACC Autism Research Database*, Interagency Autism Coordinating Committee, <https://iacc.hhs.gov/funding/data/> (last visited Jul. 1, 2021).