

September 27, 2021

Thank you for the opportunity to submit written comments on the IACC's public meeting on October 13th and 14th, 2021. In our prior comments in July 2021, ASAN emphasized the importance of using the reconvening of the IACC as an opportunity in and of itself: namely, as a means of redefining the IACC's research priorities to address the things important to autistic people ourselves. ASAN's present comments will expand upon one of the issues that is most pressing for autistic children and adults: the need for high-quality services and supports that serve autistic people of all ages and demographics.

Although autistic people are a diverse group, our need for support services is as lifelong as it is for other groups of people with intellectual and developmental disabilities (IDD). The IACC has made progress towards both directing autism research towards the priorities of autistic people. However, the direction of autism research funding and the research base for services and supports both leave much to be desired. The topics we describe below are three of those which most urgently require a comprehensive evidence base that helps determine where providers, policymakers, families, supporters, people with disabilities, and other stakeholders should direct their attention.

Supporting Access to Communication in Nonspeaking Autistic People

As ASAN noted in our July 2021 comments, there are troublingly few studies recorded in the IACC's research database for 2018 (the latest year available) which examine how best to support forms of communication for autistic people that are not oral speech. Instead, the vast majority of research available in the database focused on determining why autism impacts oral speech and ways that oral speech may be developed or improved in autistic people.¹ In ASAN's opinion, while oral speech is neither critical nor necessary to live a full life, effective communication *of some form* is. Given that approximately one-third of autistic people do not develop usable oral speech, it is imperative that significant research dollars be dedicated to understanding and scaling effective augmentative and alternative communication (AAC) approaches for any autistic individual who might need them.

Access to communication is a vital human right. Without communication, it is impossible to express thoughts, feelings, and desires and nearly impossible to direct one's own life. Autistic people may use a wide variety of possible forms of communication, including

¹ *IACC Autism Research Database*, Interagency Autism Coordinating Committee, <https://iacc.hhs.gov/funding/data/> (last visited Sept. 22, 2021).

speech sign language, written communication, behavior as communication, and AAC) devices.

There is a robust body of research showing that AAC is highly effective for individuals with disabilities that impact speech generally, including people with significant intellectual and developmental disabilities, and that access to effective communication is key to reducing “challenging behaviors” and improving quality of life. However, research is much more limited on best practices to support autistic people specifically and our associated motor and cognitive or language processing differences, and very little guidance exists for families, educators, other supporters, or autistic people ourselves looking to develop a method of communication that allows us to say more than simple requests. Effective communication means being able to express anything we might be thinking. Autistic people deserve access to communication supports that enable us to show what we know, argue with others, share memories, tell stories, ask questions, and generally say more than “I want ball please.”

ASAN therefore recommends that the IACC support and prioritize the development of substantial research on best practices for supporting robust and effective AAC for autistic people. This should include research on any supports necessary for a given communication method, such as supports for communication partners, instruction in syntax and sentence building, accommodations for motor challenges, and executive functioning supports such as reminders and prompting. Research regarding which supports or approaches are most effective for which autistic people is also badly needed. Cultural competency and cultural relevancy of alternative communication methods are also significant areas in need of research.

Assisting Individuals in Addressing Challenging Behavior

Challenging behavior (such as self-injurious or aggressive behavior) rarely arises without a specific cause. It often represents an urgent unmet need, especially if the person lacks a form of effective communication. Frequently, this need has been found to be related to an underlying physical or mental health condition, or to traumatic experiences. Autistic people are known to experience a myriad of co-occurring physical and mental health conditions, and to experience trauma at a higher rate than the general population. In other cases, it can be the result of frustration with an inability to communicate or an attempt to alleviate distress. Currently, autistic people who struggle with challenging behavior, especially autistic people with intellectual disabilities and limited or no oral speech, lack access to accessible mental health services and are typically only offered behavior modification programs or psychotropic medication, with little attempt to address their underlying needs. This is an urgent human rights crisis.

In all cases, autism research that has the goal of reducing challenging behavior should attempt to understand and address the root cause of that behavior in the form of providing supports and services tailored to specific needs and situations. However, this is not how autism research has been prioritized. According to the IACC's own 2017-2018 Research Portfolio Analysis Report, nearly half of services and supports funding is directed towards practitioner training, rather than research, while none of the remainder is directed towards helping autistic people or our supporters manage our own physical and mental health.² IACC Research Question 5's entries in the Autism Research Database contain only a few studies directly addressing these issues.³ Although IACC Research Question 6, "Lifespan Issues," includes a few studies that do address which services and supports help autistic people manage our mental and physical health, the vast majority of studies are specifically directed at the concerns of transition-age youth - only one subgroup among the many autistic people in need of high-quality services and supports to help manage daily living and co-occurring conditions.⁴ This deficit is not made up for by the Strategic Plan workshops that focused on these topics - one of which focused excessively on medication-based solutions and an extremely medicalized view of self-injurious and aggressive behavior, and endorsed highly controversial approaches of dubious merit and ethics such as Electroconvulsive Therapy.⁵

ASAN recommends that the IACC lead the charge for a transformation within autism research funding, geared towards funding research that expands the number of options available to autistic people struggling with challenging behavior. Possible research topics could include: (1) best practices for identifying and addressing underlying medical, mental health, and communication needs in people with IDD who lack a means of effective communication; (2) effective provision of community-based mental health services for people with IDD, especially people who lack an effective means of communication; (3) pilot programs of particular services and supports that address these underlying needs on an individualized basis for specific populations of autistic people to determine their effectiveness; and (4) scaling effective approaches and building the capacity of providers to support people with IDD who may struggle with challenging behavior safely and humanely

² To some extent, this may be due to the design of Question 5's Objective and subcategory design. Since neither directly mention services and supports that address co-occurring conditions, it is possible that studies on these topics exist that are filed under, for example, the Question 6 subcategories "family well-being and safety" or "community inclusion programs" instead, since the subcategories largely remain the same between reports.

³ *IACC Autism Research Database*, Interagency Autism Coordinating Committee, <https://iacc.hhs.gov/funding/data/> (last visited Sept. 22, 2021).

⁴ *Id.*

⁵ Interagency Autism Coordinating Committee, *Strategic Plan for Autism Spectrum Disorder: 2018-2019 Update 24 (2020)*, available at https://iacc.hhs.gov/publications/strategic-plan/2019/strategic_plan_2019.pdf?version=3.

in our communities.

All this work should build on existing knowledge regarding these issues for people with IDD and challenging behavior, trauma, grief, and loss, or co-occurring mental health disabilities broadly, and should closely examine questions of cultural competence. This research should be conducted, to the maximum extent possible, in partnership with autistic people, particularly autistic people with co-occurring mental health or intellectual disabilities, autistic people who use AAC, and autistic people who currently or by history struggle with self-injury or aggression.

Supports and Services for Individuals with Intellectual Disabilities and High Support Needs

ASAN strongly recommends that the IACC prioritize research that investigates how to maximize the self-determination, community integration, and physical and mental health of autistic people with intellectual disabilities and others with the highest support needs. Although the IACC has previously highlighted research in its Summary of Advances⁶ and elsewhere on these populations (and even, indeed, on the need for more research in this area), the research base is still woefully limited. Indeed, most research on services and supports for autistic people appears to be designed to reduce the future support needs of transition-age youth or to make autistic people appear less autistic, rather than on how best to ensure a high quality of life for *all* autistic children and adults.

ASAN also strongly encourages the IACC to prioritize research on services and supports for Black, Brown, and Indigenous (BBI) autistic people with ID, autistic people with ID who use English as a second language, and other individuals on whom even less research has been done. It is critical that all autistic people, rather than a white subset, be included in services and supports research. The same support may not work equally well in all cultural contexts and demographics.

We again thank the IACC for inviting interested stakeholders to comment and help the IACC direct the future of autism research. For more information on ASAN and the autistic community's research priorities, please contact Julia Bascom, our Executive Director, at jbascom@autisticadvocacy.org.

⁶ Interagency Autism Coordinating Committee, 2019 Summary of Advances in Autism Spectrum Disorder Research 38 (May 2020), available at: https://iacc.hhs.gov/publications/summary-of-advances/2019/summary_of_advances_2019.pdf.