

NEWS

Advocates, agencies weather COVID-19 without federal autism committee

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The committee tasked with coordinating autism research and services across government agencies in the United States has not met since July 2019, leaving advocates and agencies unsupported during the COVID-19 pandemic.

The Interagency Autism Coordinating Committee (IACC) usually meets at least twice a year to hear from experts and make recommendations to the secretary of Health and Human Services. Without these regular sessions, former members say, it has been challenging for autism agencies, researchers and advocates to choreograph coronavirus-related efforts, such as **adapting autism services to telehealth** or researching what makes some people with developmental conditions **more vulnerable to COVID-19**.

“Autistic individuals and their families are **suffering during the pandemic**,” says **David Mandell**, former IACC member and professor of psychiatry and pediatrics at the University of Pennsylvania in Philadelphia. “The IACC might have been able to catalyze research and funding that provided insight into the best ways to help people, and then actually helped them.”

A federal act renewed the committee in September 2019, just as its most recent members were set to complete their term. (Committee members continued to work on their 2019 reports until March 2020.) That November, officials at the Office of Autism Research Coordination (OARC), a division of the National Institutes of Health, began soliciting nominations for the next committee.

But more than a year after that nomination window closed, OARC had yet to name any new committee members. OARC director **Susan Daniels** told *Spectrum* in September 2020 she was hopeful that new committee members would be appointed that fall; in December, Daniels extended that estimate into 2021, citing the pandemic and other extenuating circumstances.

In the meantime, advocates have lost a crucial platform for communicating their priorities and

needs to the federal government, former members say.

“The failure of IACC to convene during COVID means that its members have had limited visibility or input into any kind of research on the effects of COVID on our community,” says **Sam Crane**, a former IACC member and legal director at the Autistic Self Advocacy Network.

Lack of leadership:

The IACC has responded quickly to pressing public health needs in the past.

After hearing public testimony about the prevalence of autism in Minneapolis, Minnesota’s Somali-American community, for instance, the committee announced that its member agencies would **fund a study on the subject**. The IACC also created a special subcommittee to study autism-related wandering, or **elopement**, after a presentation by the National Autism Association.

Advocacy groups and federal agencies are continuing their autism-related work, with some pandemic-specific changes. The National Institutes of Health, for example, has offered **extensions for grant applicants**. The Autism Science Foundation has awarded grants to study the effectiveness of virtual services, as well as ‘pivot grants’ to help researchers move their work online. More than a dozen advocacy groups have petitioned the Centers for Disease Control and Prevention to **prioritize people with developmental disabilities** for access to COVID-19 vaccines.

“People should not fear that autism research has come to a stop,” says **John Elder Robison**, a former IACC member, autistic self-advocate and scholar in residence at the College of William and Mary in Williamsburg, Virginia. “The past work of IACC is absolutely still guiding research.”

But the longer the delay until the new committee meets, the more difficult these sorts of efforts will become, because relationships forged during IACC meetings won’t be maintained, warns **Alison Singer**, president of the Autism Science Foundation.

The IACC appointment process is in its “final stages,” Daniels says. She says she now expects the new committee to meet this summer.

“Addressing the pandemic’s impact on individuals with autism and their families will be a top agenda item when the IACC reconvenes.”