



Profound
Autism
ALLIANCE

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Interagency Autism Coordinating Committee

IACCPublicInquiries@mail.nih.gov

Re: Public Comment on Caregivers

Dear Esteemed Committee Members:

I write to you today on behalf of the Profound Autism Alliance, a nonprofit organization working to ensure the health and connection of the subset of autistic people who require lifetime, 24/7 care. Although every part of the vast spectrum needs and deserves these things, those with profound autism have unique experiences that we hope to elevate respectfully and effectively.

Those who provide care for this population also need and deserve health and connection, not only to ensure that they can support their loved ones throughout their lives but also to experience a good quality of life for themselves. The caregivers that we engage with are struggling in isolation with few resources. Frequently, they hesitate to raise their hands to ask for help because of the stigma and shame that they can be subjected to, sometimes by people in the disability community.

At Profound Autism Alliance, we have provided a safe space for this group called Caregivers Connected. This forum allows people to connect with each other with empathy and often with real help. Our members are moms, dads, siblings, and grandparents from every corner of the United States. This past April, we hosted the first Profound Autism Summit, and almost 600 attendees from 34 states made their way to Boston. The atmosphere was one of positivity and genuine support. It was incredible!

As members of the committee that coordinates federal autism activity, I ask that you, too, provide an atmosphere of positivity and support for this group. If you want to learn more about their lives supporting a loved one with profound autism, please take a moment to read some of the stories in our Dignity Project.

Thank you for your leadership and kindness. It is so needed.

Judith Ursitti

cofounder and president