

The Autism CARES Act Needs an Overhaul Before Reauthorization

With the pending deadline for reauthorization of the Autism CARES Act, the National Council on Severe Autism (NCSA) is urging members of Congress to seize the opportunity to pass critical and necessary updates to this long-standing legislation. Since the last reauthorization in 2019, new data and scientific discoveries have altered the landscape for the autism community and legislation regarding autism must reflect current realities. Two new findings stand out as particularly urgent:

First, the prevalence of autism continues to increase dramatically — while at the same time federal efforts to discover causes of this serious disorder have failed almost completely. What was once a very rare disorder is now affecting about 3% of all U.S. children. In some studies, the numbers are even higher, including 4.5% in California, and more than 5% in parts of New Jersey. In other words, a nearly incomprehensible portion of our children have lifelong neuro-cognitive impairment—and the CARES funding has delivered no answers for an increasingly alarmed public.

Second, it has become clear that over 60% of those diagnosed with autism are deemed to have profound or severe autism. The 27% that meet profound criteria are non-verbal, minimally verbal or have an intelligence quotient (IQ) under 50. 38% of children with autism have full intellectual disability (IQ <70), and 24% have borderline intellectual disability (IQ 71-85). For nearly all the profoundly autistic population and for many in the broader group with intellectual impairment, around-the-clock care is required — significantly increasing the service complexity and costs for care. Combining this data with additional reporting that this substantially impaired autism population will continue to grow, confirms the need for federal laws, regulations and appropriations focused on those with the highest severity ratings.

The introduction of [H.R. 7213](#) is a business-as-usual bill that fails to prioritize the most urgent issues in autism. It does not address the desperate, and fairly existential, need to finally identify the risk factors that unceasingly push up the autism rates. And it does not call out the specific and dire needs of the profound/severe autistic community. The legislation would further enhance the unjust health disparities this special population endures, keeping them at the margins of research and treatment.

The federal autism legislation should include:

- Priority funding to discover the factors causing the exponential rise in autism in the U.S.
- Recognition of profound autism – as it was defined since CARES was last reauthorized. Funding for research specific to profound autism.
- Reallocation of funding to end duplicative research — the GAO found that over 80% of autism research projects funded by the federal government are likely duplicative.
- Robust research and reporting that projects the long-term service needs and costs associated with those disabled by profound autism; and provides a framework for needed policy reform in Medicaid and associated programs.
- Replace the Interagency Autism Coordinating Committee (IACC) with an autism agency within NIH to effectively oversee and direct research, grants, and programs for the autistic community. At this time the IACC, captured by identitarian ideologies, has proven itself ineffectual in delivering meaningful guidance or results for the American public.

NCSA asks you to oppose [H.R. 7213](#) in its current form, and we support the reforms proposed by the Autism Science Foundation. Please do not hesitate to reach out to our Policy Director Jackie Kancir at policy@ncsautism.org for additional information on how we can work together to overhaul the Autism CARES Act to reflect today's very urgent realities.