



The Autism CARES Act Reauthorization:
Addressing the Needs of People with Profound Autism



The Ireland Family **FOUNDATION**

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Reauthorization of the Autism CARES Act

The Autism CARES Act (the “ACA”) must be modified to address the needs of individuals with profound autism before it is reauthorized.

I. BACKGROUND

A. Legislative History: Bipartisan Support for Autism Action

Over the past 17 years, Congress and Presidents of both parties have strongly demonstrated a national commitment to an appropriately designed and scaled federal response to autism spectrum disorder (“ASD” or “autism”). They understood the growing prevalence of ASD and both its human and fiscal costs to the nation. Unfortunately, the Combating Autism Act (the “CAA”) of 2006 (and the subsequent reauthorization and renaming of that statute as the ACA in 2011, 2014 and 2019), again due for reauthorization in 2024, is seriously outdated and in need of reinvention.

B. Statistical and Societal Changes

1. Dramatic Rise in Autism Prevalence

Autism prevalence had already increased from 1 in 150 to 1 in 110 American children over just four years before the federal autism statute was first adopted in 2006.¹ Today, the prevalence rate is one in 36.² The critical importance of addressing autism effectively with federal legislation and health care policy has increased substantially.

¹Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators; Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, United States, 2006. MMWR Surveill Summ. 2009 Dec 18;58(10):1–20. Erratum in: MMWR Surveill Summ. 2010 Aug 6;59(30):956. PMID: 20023608.

²Maenner MJ, Warren Z, Williams AR, Amoakohene E, Bakian AV, Bilder DA, Durkin MS, Fitzgerald RT, Furnier SM, Hughes MM, Ladd-Acosta CM, McArthur D, Pas ET, Salinas A, Vehorn A, Williams S, Esler A, Grzybowski A, Hall-Lande J, Nguyen RHN, Pierce K, Zahorodny W, Hudson A, Hallas L, Mancilla KC, Patrick M, Shenouda J, Sidwell K, DiRienzo M, Gutierrez J, Spivey MH, Lopez M, Pettygrove S, Schwenk YD, Washington A, Shaw KA. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ. 2023 Mar 24;72(2):1–14. doi: 10.15585/mmwr.ss7202a1. PMID: 36952288; PMCID: PMC10042614.



2. Explosive Growth in Costs for Individuals with Autism

Research on the economic burden of autism indicates that annual direct medical, direct non-medical, and productivity costs combined will be, conservatively, \$461 billion by 2025 and finds that, if the prevalence of ASD continues to grow as it has in recent years, ASD costs will likely far exceed those of diabetes and ADHD by 2025.³ On average, medical expenditures for individuals with ASD are 4.1 to 6.2 times greater than for those without ASD.⁴

3. Wasteful Use of Taxpayer Funds

Unfortunately, a General Accounting Office (the "GAO") study has uncovered that much, if not most, of the significant taxpayer investment in research since the passage of the CAA has not been utilized productively. Specifically, the GAO report states, "Eighty-four percent of the autism research projects funded by federal agencies had the potential to be duplicative."

This further supports our position that the law should be renewed only if it can be remade to be effective.

Congress and the President have the ability, and the duty, to rectify this situation.

³ Leigh, J.P., Du, J. Brief Report: Forecasting the Economic Burden of Autism in 2015 and 2025 in the United States. *J Autism Dev Disord* 45, 4135–4139 (2015). <https://doi.org/10.1007/s10803-015-2521-7>.

⁴ Shimabukuro, Tom & Grosse, Scott & Rice, Catherine. (2008). Medical Expenditures for Children with an Autism Spectrum Disorder in a Privately Insured Population. *Journal of autism and developmental disorders*. 38. 546–52. [10.1007/s10803-007-0424-y](https://doi.org/10.1007/s10803-007-0424-y).

⁵ <https://www.gao.gov/products/gao-13-232>



II. ADDRESSING AN UNDERSERVED POPULATION: INDIVIDUALS WITH PROFOUND AUTISM

A. Definition of Profound Autism

Individuals on the autism spectrum have a huge disparity of needs and challenges.⁶ To provide needed clarity, the term “profound autism” was recently defined,⁷ and its estimated prevalence among children was measured by the Centers for Disease Control and Prevention. The definition of profound autism included children who were nonverbal, minimally verbal or had an intelligence quotient under 50.⁸ The report found that, across the birth cohorts, the average percentage of 8-year-old children with profound autism among those with autism was 26.7%.

B. Needs and Costs to Society

People with profound autism require round-the-clock care to assist with daily living activities and, often, to keep them safe from self-injurious behaviors, wandering, seizures and other challenges that severely threaten their lives and health. Results of a 30-year longitudinal study showed that the outcomes of people with profound autism are drastically different and far worse than those of people who are non-profound.⁹

⁶ Since the law was originally adopted, the Diagnostic and Statistical Manual of Psychiatric Disorders (DSM), which defines autism, was revised, and the five types of autism (including Autistic Disorder and Asperger’s Syndrome) were collapsed into a single diagnosis of Autism Spectrum Disorder. The inclusion of people with the relatively mild condition of Asperger’s Disorder into the fold of ASD has sown considerable confusion. Many now view ASD as a strengths-based condition, overshadowing the dire realities suffered by those with more classic forms of autism. In addition, the neurodiversity movement, while promoting acceptance for many with autism, has not realistically addressed the dramatically different needs of people with profound autism.

⁷ Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, Carr T, de Vries PJ, Dissanayake C, Divan G, Freitag CM, Gotelli MM, Kasari C, Knapp M, Mundy P, Plank A, Scahill L, Servili C, Shattuck P, Simonoff E, Singer AT, Slonims V, Wang PP, Ysraelit MC, Jellett R, Pickles A, Cusack J, Howlin P, Szatmari P, Holbrook A, Toolan C, McCauley JB. The Lancet Commission on the future of care and clinical research in autism. *Lancet*. 2022 Jan 15;399(10321):271-334. doi: 10.1016/S0140-6736(21)01541-5. Epub 2021 Dec 6. Erratum in: *Lancet*. 2022 Dec 3;400(10367):1926. PMID: 34883054.

⁸ The CDC report, titled “The Prevalence and Characteristics of Children with Profound Autism, 15 Sites, United States, 2000–2016,” Hughes MM, Shaw KA, DiRienzo M, et al. *The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000–2016*. *Public Health Reports*. 2023;0(0). doi:10.1177/0033354923116355. The paper was published in April 2023 in the peer-reviewed scientific journal *Public Health Reports*, the official journal of the Office of the U.S. Surgeon General and the U.S. Public Health Service, and analyzed population-based surveillance data from the Autism and Developmental Disabilities Monitoring Network for 20,135 8-year-old autistic children aged 8 during 2000–2016. Compared with children with non-profound autism, children with profound autism were more likely to be female (though male prevalence remained much higher than female overall), from racial and ethnic minority groups, of low socioeconomic status, born preterm or with low birth weight, have self-injurious behaviors, have seizure disorders, and have lower adaptive scores. In 2016, the prevalence of profound autism in the general population was 4.6 per 1,000 8-year-olds or 1 in 218, a 1.7-fold increase from the 2000 prevalence of .286%. The prevalence of non-profound autism increased at a higher rate, from .394% to 1.426%. The cohort with non-profound autism includes autistic children with intellectual disability, but IQs of 50–70, as well as those without intellectual disability, whose medical and support needs are not comparable to those with an intellectual disability or minimal language.

⁹ Lord C, McCauley JB, Pepa LA, Huerta M, Pickles A. Work, living, and the pursuit of happiness: Vocational and psychosocial outcomes for young adults with autism. *Autism*. 2020 Oct;24(7):1691-1703. doi: 10.1177/1362361320919246. Epub 2020 May 20. PMID: 32431163; PMCID: PMC7541415.



There are still almost no meaningful advances toward prevention or treatment for those who struggle with profound autism, nor adequate services, across the lifespan of needs, for those living with this isolating disability. There has been a strong trend away from research on matters affecting those with profound autism, and today we spend less per person with profound autism, seeking the scientific answers to these questions, than at the original passage of the CAA.

Now more than ever, research funds should be invested to detect causes, identify avenues for prevention and improve the lives of those with profound needs. People with profound autism often face a lifetime of pain and their families a lifetime of worry. Unable to fully communicate their distress and sentenced to a much shorter life expectancy than their peers,¹⁰ people with profound autism struggle to find medical care. Services are inadequate in both quality and availability. Their families face financial hardship due to sharp loss of income and vastly higher expenditures.

C. Neurodiversity Challenges and Misconceptions

Unfortunately, in recent years, the federal policy response to these stark realities of individuals with profound autism has been neutered. The ideological filter promoted by advocates without disability or the life-limiting realities of profound autism has advanced a dangerous fiction that the profoundly autistic are merely gifted with diverse forms of being human, and not in need of any particular policy attention.

Those advocating for the unique needs of the individuals and families facing profound autism wish to take nothing away from anyone else, but cannot comprehend intentionally pushing our government and broader society away from also responding properly to, or even recognizing, the suffering and acute needs wrought by profound autism.

Failure to address profound autism is a critical and crucial example of America's ideological polarization and the inability of many to hold two true ideas in their minds simultaneously. The truth is that for some people, autism may be a gift, while the simultaneous truth is that for other people, autism symptoms are a tremendous burden, a lifelong disorder, for which society should seek understanding, prevention and medical intervention. The tragic irony of the neurodiversity movement, which has dominated federal autism policy for a decade or more, is that, while it is a potent civil rights movement, it has itself resulted in the denial of basic human rights to those suffering with profound autism.

¹⁰ Tatja Hirvikoski et al. Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*. Jan 2018.

III. PROPOSED SOLUTIONS

A. Government Structures

1. NIH Autism Program

A new entity, the Office of Autism Research (“OAR”) should be established, modeled on the statute creating the highly successful Office of AIDS Research.

The OAR should be funded through a separate line item in the appropriations bill funding the National Institutes of Health (the “NIH”). That line item should include all funds to be spent on autism by the NIH for each fiscal year, with the OAR responsible for distributing funds to any other appropriate entity within the NIH for research purposes, subject to a “strategic plan for autism research” required to be revised annually by the OAR. The Interagency Autism Coordinating Committee (IACC), which was created by the CAA, should be eliminated or replaced in the NIH by the establishment of the OAR as the new lead entity for the direction of all NIH research on autism. The OAR should be advised by two panels: a panel of experts and stakeholders on profound autism, and another on non-profound autism. The newly revised act should authorize for appropriation an initial budget for the OAR that is at least double the amount that the NIH has calculated as its research spending on autism in the fiscal year prior to the enactment of the new statute.

It should be required by statute that at least half of the funds to be expended in each fiscal year by the OAR will be directed to basic science and translational medicine related to the nearly 27% of autism diagnoses meeting the definition of profound autism, given that this portion of the autism diagnoses contains persons of unique medical need who are frequently excluded from autism research.¹¹

The OAR shall be directed by a Presidential appointee, with Senate confirmation.¹² The OAR shall create metrics for the evaluation of progress on the objectives of the strategic plan and annually review the return on investment of the program. The OAR shall also be responsible for assessment of inappropriate duplication of research and for taking steps necessary to correct such duplication.

With respect to the 50% of research funds to be expended each year by the OAR on profound autism, an advisory panel of parents or other caretakers of persons with profound autism shall be established. This integration panel for this purpose would be modeled after the one existing within the Congressionally Directed Medical Research Programs.

¹¹ Stedman, Amy & Taylor, Briana & Erard, Michael & Peura, Christine & Siegel, Matthew. (2019). Are Children Severely Affected by Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature. *Journal of Autism and Developmental Disorders*. 49. 10.1007/s10803-018-3844-y.

¹² This process would model that of the National Cancer Institute.



The integration panel for profound autism to the OAR shall have voting rights with respect to the drafting of the annual strategic plan for autism research, as well as with respect to grant requests presented to the OAR for the award of research funds on profound autism.

2. Office of National Autism Policy Coordination

To facilitate interagency and interdepartmental coordination beyond the entities of the Department of Health and Human Services (the "HHS"), and to address the lifecycle concerns of the growing number of Americans facing profound autism while medical research is underway, an Office of National Autism Policy Coordination (the "ONAPC") should be created. The ONAPC should be modeled on the statute creating the Office of National Drug Control Policy (the "ONDCP"). Like the ONDCP, the Office of National Autism Policy Coordination should be directed by an individual appointed by the President and confirmed by the Senate.

The ONAPC should be required by statute to draft and annually update a national plan relating to all aspects of the federal response to the national public health concerns posed by profound autism, extending beyond the areas covered by the HHS—including but not limited to issues affecting the Department of Defense, Department of Justice, Department of Labor, Department of Education, Department of Homeland Security, Department of Housing and Urban Development, and the Environmental Protection Agency.

In drafting the national autism policy plan, the director of the ONAPC should be required by statute to consult with a citizens advisory panel. The statute should require topics in the national autism policy plan to include, but not be limited to, wandering prevention and response, including training for law enforcement/first responders/search and rescue personnel. The policy plan should also be required to include provisions to address the causes of premature death in the autism community, which are estimated to be twice that of the general population, including epilepsy, drowning, traffic-related fatalities, falls, suffocation, suicide and unrecognized co-occurring medical conditions.

B. Enhanced Services for Individuals with Profound Autism

1. Standard of Medical Care

The statute should redirect the Health Resources and Services Administration autism activities to include the development of a special patient standard of care for the medical treatment of persons with profound autism, including but not limited to in the setting of emergency room care, including pain management, and the investigation and treatment of co-occurring medical conditions.

2. Adults with Autism

Regarding the provision of services to persons with profound autism, the statute should create demonstration grant programs to assist states with service provision and to provide services for adults with autism. It should authorize the GAO to study the financing of autism treatment and services, including housing needs, as well as current public and private insurance coverage for autism treatment and support services, and identify demographic and regional disparities in access to care. The GAO should be required to make recommendations for how to finance treatment and care services so as to remove both cost and geographic barriers and attain a uniform baseline of coverage across the United States.

IV. CONCLUSION

The Autism CARES Act should be reauthorized, but only if modified as suggested in this paper to rectify outdated policies and to address the challenges of individuals with profound autism.

