

Reform the Combating Autism Act

Why Congress Must Take Action to Reform Deeply Flawed Legislation

Since 2008, the federal government has spent almost \$1 billion in autism research, with little concrete results for autistic people and their families. Despite significant investment of taxpayer dollars this area, relatively little funding has gone towards the areas that might make the most difference. As the Combating Autism Act comes up for re-authorization this year, Congress should incorporate reforms to improve the lives of autistic people and increase the impact of taxpayer dollars.

- **CAA Re-authorization must re-balance the autism research agenda:** According to the HHS Office of Autism Research Coordination, only 2.4% of NIH's autism research funding goes towards research on services and only 1.5% toward research on autistic adults¹. These low funding figures actually overstate the level of funding that went to these areas. In 2010, over 10% over the NIH's services-related research funding went toward a project focused on use of quality-adjusted life years (QALYs) to measure whether services for autistic children were 'cost-effective'. QALYs are a means of determining precisely what percentage a year in the life of a disabled person is worth as compared to a non-disabled person. Their use in allocating funds for state Medicaid programs has been deemed a violation of the Americans with Disabilities Act².
- **Prioritize Funding for Autistic Adults:** The low priority given to the issues facing autistic adults in autism research and funding contributes to the low rates of employment and higher education access faced by autistic adults today. 1 in 3 autistic adults have no access to paid employment, college or technical school in the seven years after graduation, a rate that is significantly below that faced by every group of people with disabilities³.
- **Reform the Inter-agency Autism Coordinating Committee (IACC):** Although the IACC is charged with advising the HHS Secretary on all autism-related issues, the vast majority of IACC activities have focused on research, rather than recommendations on services, supports and rights protection. By moving the IACC from NIH to the newly created Administration for Community Living, the IACC will be able to focus on the broad scope of its mandate. In addition, Congress should require that no less than half of IACC public members be individuals on the autism spectrum.
- **Use Respectful Language in CAA Re-authorization:** Language associated with "combating autism" is inconsistent with the preferences of most autistic people and their families. In any re-authorization, Congress should modify the title of CAA to bring it in line with respectful language use in the autism and developmental disability community.
- **If CAA expires, federal funding for autism programs will continue uninterrupted:** Although CAA carries with it a sunset provision for September 30th, 2014, all of the activities funded under it with the exception of a single advisory committee (the IACC) carry with it separate statutory authorization. According to testimony to the House Energy and Commerce Committee from Dr. Thomas Insel, Director of the National Institute for Mental Health, authorization and funding for all CAA programs except the Inter-Agency Autism Coordinating Committee (IACC) are "authorized to continue with or without reauthorization of the CAA."

The Autistic Self Advocacy Network is looking forward to working with Congressional offices and allied organizations on this issue. Please direct comments, questions or inquiries regarding CAA Re-authorization to ASAN's Director of Public Policy, Samantha Crane, at scrane@autisticadvocacy.org.

¹ IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool, Funder listing, <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/funders?fy=2010>

² Sullivan, L. (1992, January 9). Oregon Plan is Unfair to the Disabled [Letter to the Editor]. New York Times. Available online at <http://www.nytimes.com/1992/09/01/opinion/l-oregon-health-plan-is-unfair-to-the-disabled-659492.html>.

³ Shattuck, P, et. al. Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder. Pediatrics. May 2012. Available at: <http://pediatrics.aappublications.org/content/early/2012/05/09/peds.2011-2864.abstract>



The Autistic Self Advocacy Network (ASAN) is a non-profit organization run by and for autistic people. ASAN provides support and services to individuals on the autism spectrum while working to change public perception and combat misinformation. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research and the development of autistic cultural activities. www.autisticadvocacy.org