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Memorandum on CAA Re-Authorization

Date: January 26th, 2014

To: Members of Congress and relevant staff

From: Ari Ne'eman, President, Autistic Self Advocacy Network
Samantha Crane, Director of Public Policy, Autistic Self Advocacy Network

Subject: Upcoming Re-Authorization of the Combating Autism Act

This memorandum articulates the position of the Autistic Self Advocacy Network (ASAN) with respect to the proposed re-authorization of the Combating Autism Act (Public Law 109-416). The Autistic community has significant concerns regarding CAA. The law, which passed without the involvement of the self-advocacy movement, is a source of frustration for many autistic people and family members who are concerned by the law's lack of investment in the needs of autistic adults, the overwhelming bias in favor of basic biomedical and causation-related research in federal autism research funding, the minimal opportunities for autistic people to provide meaningful input into CAA programs, and the offensive rhetoric in the law's title. While ASAN opposed the prior re-authorization of CAA in 2011 due to the absence of any alterations whatsoever to the legislation, we are interested in working with your office to modify CAA so as to make it respectful to and in line with the priorities of those it is intended to serve. It is our belief that it is possible to accomplish this without altering the bill so significantly as to make re-authorization politically difficult. To accomplish this goal, we have articulated five major priorities for CAA Re-Authorization. We look forward to working with your office to facilitate their inclusion in the re-authorization legislation.

1) **Re-Balance the Autism Research Agenda to Include Research on Effective Services and Adults**

Only a small fraction of federally funded autism-related research focuses on provision of effective services or on the needs of autistic adults. These research areas are crucial in order to improve the quality of life of autistic people throughout our lives. In 2010, the most recent year in which data is available, the National Institutes of Health (NIH) allocated only 2.4% of its autism research funding toward services-related research and only 1.5% toward research on the needs of adults.¹

These low funding figures actually overstate the level of funding that actually went toward research on services and the needs of adults. For example, 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 cost-effectiveness of interventions for autistic children.² The use of QALYs to measure cost-effectiveness has been criticized as discriminatory against individuals with disabilities and has been deemed a violation of the ADA when states have proposed to utilize the QALY system to allocate resources in their Medicaid

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 *Id.*

programs.³ As a result, the Affordable Care Act specifically prohibited the newly created Patient-Centered Outcomes Research Institute (PCORI) from using or promoting QALYs as a threshold to determine cost-effectiveness.⁴

In addition, over 30% of the NIH's adult-oriented research funding in 2010 focused on the needs of caregivers of autistic adults rather than the needs of those adults themselves. Another project, which accounted for 9% of the NIH's services-related funding, was focused on "mindfulness" techniques to reduce stress among caregivers and not on research regarding the provision of services to autistic individuals.⁵ While this funding may be worthwhile, it further dilutes the already miniscule percentage of funds devoted to researching the needs of those most directly impacted by autism – autistic people ourselves.

Congress should ensure that a greater portion of autism research funding is used to study effective service provision and the needs of autistic adults. This could be accomplished by shifting a portion of autism research funding from NIH to the National Institute on Disability and Rehabilitation Research (NIDRR) or the Projects of National Significance (PNS) program within the Administration on Intellectual and Developmental Disabilities (AIDD), both of which have existing mechanisms to fund research that directly relates to services and adult issues faced by individuals on the autism spectrum. These agencies have specific expertise in the needs of autistic adults, autistic children and the importance of services to improve the quality of life of autistic people across the lifespan. Alternately, Congress could require the NIH to allocate a specific percentage of autism research dollars to services and adult research.

2) **Prioritize Funding for Autistic Adults**

Congress should establish a demonstration grant for services for children, transitioning youth, and adults, such as that proposed in Dodd's 2010 CAA re-authorization proposal.⁶ This grant would fund projects to expand services for autistic adults and those transitioning from secondary education to post-secondary education or employment. It would also fund projects to improve quality of life of autistic individuals throughout their lifespan, including expansion of community-based supports, nutrition and health programs, and improvements in personal safety of autistic children and adults.

We also support the broadening of CDC's research on the prevalence of autism to include adults. At present, the CDC focuses on prevalence of autism among eight-year-old children.⁷ Adult prevalence studies conducted in the United Kingdom by the National Health Service revealed valuable information on the number and need of adults on the autism spectrum in that country.⁸

³ See, e.g., 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/1-oregon-health-plan-is-unfair-to-the-disabled-659492.html>.

⁴ 42 U.S.C. § 1320e-1(e).

⁵ IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool, Funder listing, <https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/funders?fy=2010>.

⁶ Combating Autism Reauthorization Act of 2010, S. 4044 111th Cong. § 5(d) (2010).

⁷ Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. MMWR 2012;61(SS03):1-19. Available online at http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w.

⁸ Health & Social Care Information Centre. Estimating the Prevalence of Autism Spectrum Conditions in Adults - Extending the 2007 Adult Psychiatric Morbidity Survey. January 31, 2012. Available online at <http://www.hscic.gov.uk/pubs/autism11>.

3) Transfer primary responsibility for management of the Interagency Autism Coordinating Committee (IACC) from the National Institutes of Health to the Administration on Intellectual and Developmental Disabilities (AIDD) within the Administration for Community Living (ACL).

The Interagency Autism Coordinating Committee (IACC) is responsible for, among other things, developing a strategic plan for autism research and making recommendations to the Secretary of Health and Human Services regarding federal autism-related activities.⁹ While the IACC's responsibilities extend well beyond research, the vast majority of IACC activity has focused on its research responsibilities, rather than advising the Secretary on issues relevant to autism services, supports and rights protection.

It is vitally important that the IACC focus on the service needs of autistic children and adults. To further this goal, responsibility for management of the IACC – including responsibility for providing management and support services, preparation of meeting agendas, and convening meetings, should be transferred to the Administration on Intellectual and Developmental Disabilities (AIDD). AIDD's Commissioner should be charged with chairing the IACC and overseeing the Office of Autism Research Coordination. To date, the IACC has devoted relatively little attention to the services and supports needs of autistic people across the lifespan, owing largely to its presence within an infrastructure devoted primarily to basic research. By placing the IACC within ACL and AIDD, the IACC would also be better aligned with its sister committee, the President's Committee on People with Intellectual Disabilities (PCPID).

4) Change the composition of the IACC to require that at least half of the public members be autistic people and to add representation by DOJ, NCD, HUD and other relevant service-oriented federal agencies.

Autistic people are uniquely suited to assessing which research and services programs are most needed in order to improve their own lives. However, the IACC is only currently required to have one of its members be an individual with an autism spectrum diagnosis. The IACC's authorizing statute should be revised to require that 50% of the public members of the IACC be individuals with an autism spectrum diagnosis.

The current IACC membership also does not include representatives from key agencies that provide services to autistic individuals. Congress should require that the Department of Justice, National Council on Disability, and Department of Housing and Urban Development, and Department of Labor, in addition to other relevant service-oriented federal agencies, be represented in the IACC.

5) Change the name of the Combating Autism Act to end the use of stigmatizing language.

By naming its primary autism-related legislation the "Combating Autism Act," Congress devalues the lives of autistic individuals. The purpose federal autism-related activities should not be to "combat" autism but rather to support autistic individuals and their families. We would be glad to work with your office to identify a less stigmatizing name, such as the Autism Community Empowerment Act or the Autism Assistance and Bill of Rights Act. The latter would bring the legislation in line with the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

We look forward to working with your office on these issues. Please don't hesitate to contact us at aneeman@autisticadvocacy.org or scrane@autisticadvocacy.org.

⁹ Interagency Autism Coordinating Committee, Charter, <https://iacc.hhs.gov/about/charter.shtml>.