

July 10, 2019

Chairwoman Anna Eshoo
Health Subcommittee
House Energy & Commerce Committee
202 Cannon House Office Building
Washington, DC 20515

Ranking Member Michael Burgess
Health Subcommittee
House Energy & Commerce Committee
2161 Rayburn House Office Building
Washington, DC 20515

Chairman Frank Pallone
House Energy & Commerce Committee
2107 Rayburn House Office Building
Washington, DC 20515

Ranking Member Greg Walden
House Energy & Commerce Committee
2185 Rayburn House Office Building
Washington, DC 20515

Dear Health Subcommittee Chairwoman Eshoo, Health Subcommittee Ranking Member Burgess, Chairman Pallone, and Ranking Member Walden:

We write to you to voice our support for the greater inclusion of people with autism themselves in the current text of the Autism CARES Act reauthorization (H.R.1058/S.427), as proposed by The Arc of the United States, the Autistic Self Advocacy Network, and the American Network of Community Options & Resources (ANCOR). We are all organizations that have either already affirmatively supported the current draft of Autism CARES or that have remained neutral pending this adjustment. We have come together to demonstrate our broad support for a manager's amendment or other final version of Autism CARES which incorporates a single, narrow change: increasing the representation of self-advocates on the Interagency Autism Coordinating Committee (IACC).

The IACC oversees all federal autism research spending and is tasked with creating an agenda to drive research priorities. Presently, out of 12 public members, there are only 2 self-advocates on the [IACC](#)--barely 7% of the full IACC membership. This imbalance violates basic principles of the disability community, which recognizes that people with disabilities--including people with the most significant disabilities--should be at the center of research and policy regarding their lives. In accordance with the core values of our community, we support updated bill text requiring that one-third of non-federal IACC members be autistic people. This can be achieved simply by adding 3 additional seats to the IACC public membership. This would still mean that only 13-15% of the full IACC would be self-advocates but would nonetheless represent a meaningful step forward.

This modest adjustment also represents a no-cost way to increase the efficacy of, and better realize the intent, of Autism CARES itself. Currently, the vast majority of federal autism research spending goes towards biomedical research, with little attention paid to research that can directly benefit the lives of people with autism. Self-advocates from all walks of life have consistently advocated for a research agenda with a heavier emphasis on applied research, addressing issues such as sleep and eating disorders, communication, health care, mental health and suicide, and lifespan services. By increasing the number of self-advocates on the

IACC, Congress can help to ensure that researchers utilizing federal dollars are more accountable to the people their research would ultimately serve.

This proposed change is consistent with the Consortium for Citizens with Disabilities' [consensus principles regarding Autism CARES](#), and will enhance the ability of the legislation to implement its goals, as articulated throughout the text, of increased support and quality of life for autistic people across the lifespan through research and training. For those of us already on the record in support of this reauthorization, this change will only strengthen our support. For those of us not yet in support, this will enable us to move forward.

In unity,

Allies for Independence

American Association on Health & Disability (AAHD)

American Association of People with Disabilities (AAPD)

American Music Therapy Association

American Network of Community Options & Resources (ANCOR)

The Arc of the United States

Association of Assistive Technology Act Programs (ATAP)

Association of Programs for Rural Independent Living

Autistic Self Advocacy Network (ASAN)

Autistic Women & Nonbinary Network

Bazelon Center for Mental Health Law

Center for Public Representation

Council of State Administrators of Vocational Rehabilitation (CSAVR)

Disability Rights Education and Defense Fund (DREDF)

Easterseals

Family Voices

The Jewish Federations of North America (JFNA)

Lakeshore Foundation

Lutheran Services in America – Disability Network

National Association of Councils on Developmental Disabilities (NACDD)

National Association of State Directors of Special Education (NASDSE)

National Coalition for Mental Health Recovery

National Council on Independent Living (NCIL)

Network of Jewish Human Services Agencies

Not Dead Yet

United Spinal Association

Cc: Rep. Chris Smith

Rep. Mike Doyle