

September XX, 2014

Secretary Sylvia Burwell
U.S. Department of Health and Human Services
330 Independence Ave, SW
Washington, DC 20201

Director Francis Collins
National Institutes of Health
900 Rockville Pike
Bethesda, MD 20892

Dear Secretary Burwell and Director Collins:

Following on the passage of the Autism CARES Act, we write to express our interests and priorities surrounding implementation of the law. The recent enactment of the Autism CARES Act presented an important opportunity to examine the state of federal autism research and other autism-related programs. In the process of enacting this legislation, our offices heard from numerous constituents, advocates, and federal agencies about federal autism research and programs to date. Those discussions addressed concerns with existing efforts and suggestions on ways in which these activities could be improved.

We are particularly concerned with issues raised by individuals with autism and self advocacy organizations. They feel very strongly that their voices are not adequately heard in federal autism policy deliberations and programs. We wanted to share their main concerns with you.

Those concerns include:

- The Inter-Agency Autism Coordinating Committee (IACC), the body tasked with developing the HHS Strategic Plan for Autism Research, currently has only two individuals on the autism spectrum and no member from a self advocacy organization out of fourteen public and twenty-eight total members.
- Individuals with autism are not adequately represented in federally-funded programs, such as the Leadership and Education in Neurodevelopmental Disabilities (LEND) programs, which train students interested in careers in disability services and supports.
- Very little autism funding is currently devoted to the daily needs of individuals with autism and their families. For example, according to the IACC's Portfolio Analysis Web Tool, in 2010 (the most recent year data was available) only 2.4% of NIH's autism research budget went towards research on improving the quality of services and only 1.5% went towards research on the needs of autistic adults.

We believe those concerns should be addressed in the implementation of the Autism CARES Act. We strongly support several recommendations we heard from the self advocacy community.

Those recommendations include:

- Increase representation of autistic individuals and self-advocacy organizations on the IACC.
- Ensure that individuals with autism are represented in training programs funded through the Autism CARES Act.
- House the National Autism Spectrum Disorder Initiative within the Administration on Community Living or the Secretary's principal advisor on disability issues.

We urge you to implement the Act in a manner that would address the concerns that we've heard and incorporate the recommendations of the self advocacy community. Autistic individuals should have a voice in federal policy deliberations impacting their lives. To borrow from the long time slogan of the disability rights movement, "Nothing About Them, Without Them." Thank you for your attention to our request.

Sincerely,

cc: Administrator Kathy Greenlee, Administration on Community Living
Deputy Administrator Sharon Lewis, Administration on Community Living

Congressional offices should contact Waverly Gordon in Rep. Schakowsky's office to sign on.