



August 11, 2017

The Honorable Melissa Ortiz
Commissioner
Administration for Community Living
330 C St., SW
Washington, DC 20201

Submitted by email to: P3I-comments@acl.hhs.gov, melissa.ortiz@acl.hhs.gov

Dear Commissioner Ortiz,

The undersigned members of the Developmental Disabilities, Autism, and Family Support Task Force of the Consortium for Citizens with Disabilities (CCD) write to express deep concerns about the proposed budget restructuring, called the Partnerships for Innovation, Inclusion, and Independence (PIII), that will impact the State Councils on Developmental Disabilities and other key programs not legislatively intended to be consolidated.

CCD is the largest coalition of national organizations working together to advocate for national public policy that ensures full equality, self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The mission of our specific task force is to advocate for federal public policies that directly relate to individuals with developmental disabilities, autism spectrum disorders, family supports and the prevention of child abuse and neglect including the Developmental Disabilities Assistance and Bill of Rights Act (DD Act).

While we understand that the proposed budget restructure - which consolidates activities carried out by the State Councils on Developmental Disabilities (DD Councils), Independent Living, and Traumatic Brain Injury programs into a single state grant program - seeks to achieve \$57 million in savings for the upcoming fiscal year, we believe this would significantly disrupt the goals and achievements of these programs while also counteracting the efficient funding mechanisms and primary intent of the legislation that created them.

As a task force focused on developmental disabilities, our concern is acutely focused around changes to the DD Councils. The DD Councils serve as a required and essential arm of the DD Act and a significant decimation of the funding for these Councils combined with their separation from their partners is extremely problematic and poses serious risks to the 50 year old program as outlined below.

Authorizing Legislation and Purpose

In order to make the changes proposed for the PIII, Congress would have to amend not only the DD Act but two other laws for the program activities involved - 1) the Rehabilitation Act of 1973, as amended, in order to eliminate Independent Living Services state grants that in part support Statewide Independent Living Councils [SILCs] and 2) the Public Health Service Act in order to eliminate State Advisory Board on Traumatic Brain Injury [SABTBI]. In addition, many DD Councils are established in state statutes and

regulations and significant time would be needed to work through state level processes to amend their authorizing legislation or regulations.

Each of the proposed activities for consolidation and significant reduction were created to address distinct disability populations and objectives. For instance, the state DD Councils address the needs of persons with developmental disabilities, conditions more likely to be recognized in early childhood than traumatic brain injury which is more likely to be acquired throughout the lifespan. Consequently, DD Councils typically work with and for persons with such conditions as Down syndrome and Autism while State Advisory Boards on TBI work for and with persons living with injuries resulting from car accidents, falls, shootings, and combat related events, among other things. Such population differences require that the existing programs have expertise in and be responsive to the unique abilities, experiences, behaviors, services, and service systems involved with each of their disability subgroups.

DD Act Program Structure

The DD Act authorizes four distinct but interdependent programs – the State DD Councils, the Protection and Advocacy (P&A) program, the University Centers for Excellence in Developmental Disabilities, and the Projects of National Significance. The DD Councils provide state planning, evaluation, and state systems changes; the University Centers for Excellence in Developmental Disabilities provide research, education, interdisciplinary training and services; the Protection and Advocacy Systems provide legal assistance to ensure that individuals receive appropriate services and are free from abuse and neglect; and the Projects of National Significance focus on the most pressing issues affecting people with developmental disabilities and their families. All four arms of the DD Act serve the same constituency and work closely at the national and state level to ensure that services are being provided in an effective and efficient manner – including through the resourceful use of limited funding. To separate the DD Councils from its DD Act partner programs would not only be unfortunate but illogical.

False Economy of Scale

The PIII proposal assumes savings based on reducing duplication of effort. However, the premise is incorrect. It would be extremely difficult to form one Council that would be able to adequately meet the variety of needs and services for such disparate disability populations and to reach consensus on how to expend limited funds for the populations.

The proposed budget of \$45 million will not adequately serve any of these three groups of individuals with disabilities. The DD Councils are funded through a formula grant unlike the other two proposed program activities so the funding structure would have to be completely rethought for PIII.

The proposed funding cuts would decimate the DD Councils which receive only a pinpoint (\$73 million in 2017) of the HHS budget and function efficiently with sometimes only one staff person per state so that the limited dollars can be used in the community and directly into the programs that impact people with intellectual and developmental disabilities. These programs include longstanding and successful trainings for parents in rural communities about how to navigate an individualized education program (IEP) and medical access for a child born with a significant developmental disability. To cut this access to parents without any other resources in their community would be devastating.

The DD Councils are one of the great displays of American democracy. The DD Act requires that the majority of members serving on a DD Council must be a person with a disability or a family member from the state, ensuring that the most impacted individuals have input into the programs and services being implemented in their communities. This approach has been successful for decades, creating the ability for children with disabilities to attend school with their peers, for parents to obtain resources about their child's disability, for adults with disabilities to return to their families from institutional settings, and for them to live, work and thrive in their communities across the country. We feel strongly that disrupting this successful program and seeking cuts to the limited funding they currently receive would have a significant long-term impact on people with developmental disabilities around the country and for that reason, we cannot support the PII initiative.

Fortunately, the House Committee on Appropriations released its report for the Labor, Health and Human Services, Education, and Related Agencies appropriations bill last month and recommend level funding in FY 2018 for the DD Councils and two of its DD Act partner programs. The Committee rejected the President's proposal, saying "The Committee does not consolidate the State Councils on Developmental Disabilities, State Independent Living Councils, and State Advisory Boards on Traumatic Brain Injury. The Committee recognizes the unique role played by each program and believes consolidation into one program will not serve the needs of people living with a disability." We urge the Administration to accept the Committee's position and not pursue the proposed consolidation further.

Sincerely,

American Civil Liberties Union

American Music Therapy Association

American Network of Community Options and Resources

American Occupational Therapy Association

American Psychological Association

Association of People Supporting Employment First

Association of University Centers on Disabilities

Autistic Self Advocacy Network

Autism Society of America

Autism Speaks

Division for Early Childhood of the Council for Exception Children

Easterseals

Family Voices

IDEA Infant Toddler Coordinators Association

Lutheran Services in America Disability Network

National Academy of Elder Law Attorneys

National Association of Councils on Developmental Disabilities

National Association of State Directors of Special Education

National Disability Rights Network

National Respite Coalition

Parent to Parent USA

TASH

The Arc of the United States

United Cerebral Palsy