



The Honorable Alex Azar
Secretary of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

May 10, 2019

Dear Secretary Azar:

As the three networks mandated to coordinate activities under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 – the State Councils on Developmental Disabilities (Councils), University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), and Protection & Advocacy Systems (P&As) that operate in every state and territory – we are writing to offer feedback about the planned reorganization within the Administration for Community living (ACL) and to request a meeting with you to discuss our concerns and share our ideas that we believe would advance your stated goals to “improve efficiency and effectiveness of the organization; strengthen infrastructure; and improve the connections between the organization and its stakeholder, grantees and consumers at the national, state and local levels.”

A foundational and intentional feature of these three programs is that they function as a developmental disabilities (DD) network drawing upon their unique roles to work in coordination and collaboration to respond to state and local needs. For decades, the DD Act has mandated that our members collaborate at the State and local level to advance our collective goals. This collaboration is the source of significant efficiencies in ensuring efforts are complementary and not duplicative. It also helps identify and elevate issues of common interest that can be addressed by all network partners acting together using their unique mandates. At the state level, policymakers, individuals with developmental disabilities and families depend on partner coordination to ensure systems function in accessible and the most cost-efficient ways. At the federal level, recent policy and program successes resulting from the coordinated efforts of the DD Act partners and ACL leadership within the Administration on Intellectual and Developmental Disabilities (AIDD) have been achieved in employment, addressing neonatal abstinence syndrome as part of the response to opioids, supporting home and community-based services funded by CMS, and addressing health and safety of individuals with developmental disabilities living in group homes.

Critical to these efforts is the leadership of career staff at ACL with a deep understanding of the DD Act partners and their unique roles in advancing the rights, health, well-being, safety, and inclusion goals of people with disabilities. Consolidating the DD Act programs under AIDD was intentional for this reason: there is a single point of administration and accountability. Housing all programs – the PCPID and Projects of National Significance, UCEDDs, Councils, P&As, HAVA, Section 292 and AT Act, Section 5 (P&A grants) – within AIDD is critical in maximizing staff expertise in oversight of the programs, streamlining knowledge sharing in support of collaboration, and setting consistent outcomes for the three programs. It is notable that the RFP and review process for all DD network grantees includes a strong requirement around documentation and planning for collaboration.

Having a single leadership representative at the career staff level has also benefited ACL in its federal interagency work by connecting other federal partners with this Network to drive innovation and quality improvements in the states. The Interagency Autism Coordinating Committee is just one such example, where senior partners from CMS, HRSA, and NIH are present. We are concerned that the Directors of the Office on Intellectual and Developmental Disabilities and the Office on Disability Service Innovation will not have the same level of stature in their interactions with federal partners outside of ACL, and will not be able to bring their expertise and the collective knowledge of our respective networks to bear in a way that informs and improves policymaking across HHS and across the federal government.

The proposed separation of the P&A's and Projects of National Significance from AIDD and from the UCEDDs and Councils creates challenges to shared work and its desired impact as envisioned by the DD Act. It also creates inefficiency within ACL, requiring the new director of the proposed Office of Disability Services Innovation to coordinate with the Office of Intellectual and Developmental Disability Programs to ensure the current level of program synergy remains uninterrupted.

We all supported the creation of the Administration for Community Living in 2012, in part because we believed that bringing together the Administration on Developmental Disabilities and the Administration on Aging would result in more policies and programs that support individuals and families to lead good lives with dignity in the community across the lifespan. We still believe in that vision, but that vision will not happen if the expertise that exists in the disability programs is not brought to bear consistently at the highest levels of ACL. We are concerned that this expertise did not inform the reorganization process, is not informing ACL's strategic priorities, and will be less important if this reorganization proposal moves forward. On behalf of the millions of Americans with intellectual and developmental disabilities and their families who we serve, we urge you to slow down the reorganization timeline to allow for the stakeholders in the disability and aging communities to be part of the process. We also urge you to keep AIDD intact, with all DD Act programs remaining together under that Administration.

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We regret that there was not involvement of stakeholders, grantees or consumers at the national, state and local levels in the drafting of the proposed reorganization. We would like to meet with you at your earliest convenience, and before the proposed reorganization moves forward, to discuss our concerns and share our ideas on how ACL might improve its structure to assure efficiencies and synergies that will advance its critical mission.

Sincerely,

Curt Decker
National Disability Rights Network

Andy Imparato
Association of University Centers on Disabilities

Donna Melzer
National Association of Councils on Developmental Disabilities

Cc: Lance Robertson, Assistant Secretary of Aging and Administrator of the Administration for Community Living