

WHAT'S HAPPENING IN WASHINGTON AND WHAT YOU NEED TO KNOW ABOUT ACL

We've been getting lots of questions about what is going on in Washington and how it does, will, or might impact our community. We had planned to provide a simple, educational guide to explain the various proposals and Congressional and Executive actions, but the more we looked, the more confusing it became, largely because, as they say, "it's really complicated," and because everything is moving and changing so quickly. The best example, at least as of today, is the Administration for Community Living (ACL), an agency within the Department of Health and Human Services (HHS). Although nothing is certain about its continued existence, or the funding streams it directs, we thought it important for you to know something about an agency that has been so incredibly impactful for SDM and SDMNY.



U.S. Capitol Building, the Legislative Branch

First, a little history. In 1975, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act, which included the formation of State Councils on Developmental Disabilities (DD Councils), Protection and Advocacy (P&A) systems, and University Centers for Excellence in Developmental Disabilities (UCEDDs). These programs, which exist in every state and territory, were consolidated into the ACL in 2012, and are funded by and housed under ACL.

From the beginning of conversations about the human right of legal capacity in the US, ACL and its three major programs have been a leading voice and champion for SDM nationally, and here in New York. ACL brought the concept to national attention by establishing the National Resource Center on SDM in 2014. SDMNY got its start through our original grant from New York's DD Council, the Developmental Disabilities Planning Council (DDPC), in 2016; New York's P&A, Disability Rights New York (DRNY), has been a trusted partner, providing invaluable expertise to us, as well as legal representation to Decision-Makers seeking termination of guardianship and restoration of their rights. One of New York's four UCEDDs, the Westchester Institute for Human Development (WIHD), has actively promoted SDM through its Community Support Network Transitions program. And, of course, WIHD gave us SDMNY Director Naomi Brickell!

So what do we know about what's happening with ACL and these valuable programs? (Although it's not our usual style, we're including links for more information.) In early April, an HHS memo leaked, indicating that ACL would be disbanded and its programs "redistributed" among three other HHS agencies (<https://www.disabilityscoop.com/2025/03/31/trump-administration-to-close-agency-promoting-community-living-for-people-with-idd/31384/>); ACL also lost "roughly half of its 200-plus employees, including most of its leadership,... including public affairs and policy teams as well as all of the regional offices that communicate with organizations in the field to ensure that the grants and services reach the intended populations" (<https://www.statnews.com/2025/04/01/hhs-firings-put-disabled-americans-at-risk/>).



The White House, the Executive Branch

Lawsuits were filed and there is currently an injunction against halting distribution of already authorized funds, but the future of ACL's three major programs, described above, was unclear. An April press release that suggested a 40% cut to the P&As has been succeeded by a current return to virtually full funding (<https://www.disabilityscoop.com/2025/05/05/nations-disability-services-system-begins-to-buckle-as-funding-threats-intensify/31439/>) as a result of advocacy on the importance of their work to the states and especially to people with I/DD and their families. ([Click here](#) to read the Report prepared by DRNY.) Like the P&As, funding for the DD Councils seems safe for the moment, but the President's budget still provides for the elimination of the UCEDDs (<https://www.disabilityscoop.com/2025/06/05/trump-budget-calls-for-major-changes-to-disability-programs/31479/>), subject, however, to Congressional approval. (For information about UCEDDs and proposed elimination [click here](#).)

SDMNY does not and cannot lobby, but we share this information about ACL and its programs to educate our community and to encourage members to share any stories they may have **about their** experiences with ACL, or through SDMNY, with their Congressional representatives.