

April 9, 2025

SPAN Parent Advocacy Network Statement on Restructuring the Department of Health and Human Services

The SPAN Parent Advocacy Network (SPAN) is NJ's federally designated Parent Training and Information Center, Family-to-Family Health Information Center, NJ State Affiliate Organization (SAO) of Family Voices, and the NJ affiliate of Parent-to-Parent USA. Our comments today are based on our years of work supporting diverse families and youth/young adults in advocacy as well as in systems improvement activities across education, employment, and health. SPAN Parent Advocacy Network is deeply concerned about the restructuring of the Department of Health and Human Services (HHS). We join many state and national organizations in expressing these concerns.

One major concern is the dismantling of the Office of Special Education Programs (OSEP) of the Department of Education and moving it into HHS. The Department of Education is a better fit for OSEP because learning for children with disabilities should be housed in the same agency as learning for all children. Children with disabilities are children first; students with disabilities are students first. When education was under the former Health, Education and Welfare, education was left up to the states and many students – including but not limited to students with disabilities - had no protection from state education departments that discriminated against them in funding, and on the basis of disability, race, ethnicity, and socio-economic status. At that time, only 1 in 5 students with disabilities were receiving an education. Furthermore, HHS would see students with disabilities under the medical model, as something to be fixed, rather than a natural characteristic of being human. We are also concerned that, if the Office on Civil Rights is moved, many students with disabilities and their families will be unable to get a free, appropriate education under the Individuals with Disabilities Act as well as under Section 504 of the Rehabilitation Act. In addition, the massive staffing cuts at the Department of Education, especially the decimation of the Office for Civil Rights, have further backlogged the investigation into complaints of civil rights violations.

We are also concerned with the reorganization plan to dismantle the Administration on Community Living. ACL helps people with disabilities live independently in their homes and communities. ACL cuts will also adversely impact Centers for Independent Living, Protection and Advocacy Programs, as well as Councils on Developmental Disabilities.



The Substance Abuse and Health Services Administration is also adversely impacted. The COVID-19 pandemic worsened mental health in the U.S. for both children and adults. Some children and adults who did not have mental illness do now, and some with pre-existing mental illness saw that their conditions were exacerbated.

Also concerning are the Centers for Disease Control and Prevention (CDC) layoffs which will negatively impact addressing health disparities for people with disabilities. This is a population recognized by the National Institutes of Health as underserved and experiencing health inequities with increased morbidity and mortality.

Disability advocates are also concerned with proposed cuts to Medicaid and family support programs like SNAP, LiHEAP, and Meals on Wheels. LiHEAP doesn't just help with utility bills but also life-sustaining equipment such as ventilators, oxygen, etc. ACL programs and Medicaid support independent living in the community. Cutting these programs will result in more people with disabilities having to enter institutional care, which incidentally research shows is 2-3 times more costly.

Dismantling ACL and minimizing the importance of SAMHSA and the Health Resources and Services Administration (HRSA) by subsuming them into a new agency has not been decided on through a thoughtful, deliberative process that involves the voices and perspectives of the people these agencies are intended to support and protect – people with disabilities, their families, and other populations with health risks. Nothing in the announcement provided these individuals and the advocacy organizations that work with them with any guarantee or sense of confidence that the vital work of these entities will continue.

All of the above proposals will negatively impact vulnerable populations. Given SPAN's foremost commitment to children and families with the greatest need due to disability or special health/mental health needs; poverty; discrimination based on race/ethnicity, gender, gender identity, sexual orientation, language, immigrant or homeless status; involvement in the child welfare or juvenile justice systems; geographic location; or other special circumstances, we oppose these moves and urge the Administration to rethink these sudden, massive changes and engage in dialogue with the intended beneficiaries of these programs.

Thank you for your consideration of our concerns and recommendations. For more information, go to <u>https://spanadvocacy.org/</u>