



May 14, 2024

The Honorable Tammy Baldwin
Chair
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies

The Honorable Shelley Moore Capito
Ranking Member
Senate Appropriations Subcommittee on
Labor, Health and Human Services,
Education, and Related Agencies

Dear Chair Baldwin and Ranking Member Capito:

On behalf of the undersigned members of the National Partnership for Pediatric to Adult Care Transition (NPPACT), we write to ask you to include report language in the FY2025 Subcommittee report regarding the need for an HHS report to identify the federal policies, investments, and programs supporting the continuity of care for young adults as they age out of the pediatric specialty care system and the many gaps that exist. As the co-chair of the Rare Disease Caucus and the Congenital Heart Defect Caucus we thought this would be of particular interest to you.

NPPACT is a multi-disciplinary group of stakeholders committed to education and advocacy for federal programs, investments, and policies, which will help ensure smoother care transitions for people with congenital and pediatric on-set, chronic, and/or disabling conditions that were initially diagnosed, treated, and managed in childhood.

Many serious, life threatening, and disabling conditions affecting children once meant a shortened lifespan and/or significantly diminished quality of life. However, due to improvements in health care, medical management, and other innovations, these once pediatric patients are now adults living with chronic conditions requiring life-long management. Yet, the nation's health care system has not kept pace and too many of these adult patients are falling through the cracks and experiencing adverse health outcomes as they transition from pediatric specialty clinics to adult health care settings.

Many health systems have deep expertise in caring for medically complex and special needs pediatric populations and have specialized clinics that offer comprehensive primary and specialty care to these patients. However, once these individuals turn 18 or 21, they are no longer permitted to be seen at these centers, and too many times they fall over the "care cliff" because there are few – if any – health care providers who can deliver specialized care to adults living with these conditions. The population of individuals affected by this "transition care cliff" is growing every year. They are experiencing poor health outcomes, adverse health events such as emergency department visits, which could be prevented if they were providing continuity of care.

Ensuring that federal programs, investments, and policies exist to address the pediatric to adult health care transition for medically complex and special needs individuals will help families experience smoother care transitions, including developing and maintaining adult care settings designed to support adults living with serious, life-threatening, and disabling conditions that were initially diagnosed, treated, and managed in childhood. And in the absence of such programs, understanding the current federal landscape will inform the community and policymakers where federal investments should be prioritized.

Therefore, NPPACT is requesting the inclusion of the following report language meant to survey and find gaps in our nation's federal policies, investments, and programs supporting the continuity of care for young adults as they age out of the pediatric specialty care system. Please consider supporting the following report language in the Fiscal Year 2025 Labor, Health, and Human Services Appropriations bill:

Department of Health and Human Services

Office of the Secretary, *General Departmental Management*

“Medically-Complex and Special Needs Adolescents Aging Out of the Pediatric Care System.—The Committee requests an update in the fiscal year 2026 congressional budget justification on what AHRQ, CDC, CMS, HRSA/MCHB, and NIH are undertaking and/or funding with respect to efforts to support and facilitate continuity of care for medically-complex and/or special needs adolescents who are aging out of the pediatric care system.”

Thank you for taking our request under consideration. If you have any questions, please reach out to Sara Struwe, President & CEO, Spina Bifida Association, sstruwe@sbaa.org or (202) 618-4747.

Sincerely,

Adult Congenital Heart Association
American Society for Bone and Mineral Research
Arthritis Foundation
Bone Health and Osteoporosis Foundation
EveryLife Foundation for Rare Diseases
Hydrocephalus Association
National Down Syndrome Society
National Health Council
Osteogenesis Imperfecta Foundation
Parent Project Muscular Dystrophy
Spina Bifida Association
The Arc of the United States
The National Alliance to Advance Adolescent Health
Tourette Association of America
Turner Syndrome Foundation