



## **The Need for Continuity of Care for Young Adults Transitioning from Pediatric Specialty Clinics**

The Spina Bifida Association (SBA) and the Hydrocephalus Association (HA) have convened a coalition to address unmet needs among patient communities that have a growing number of young adults transitioning from pediatric specialty clinics. 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.

Many health systems have deep expertise in caring for 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 within 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 and SBA and HA seek to work with partners throughout the patient advocacy community to ensure that our nation's federal policies, investments, and programs begin to reflect the growing need for continuity of care for young adults as they age out of the pediatric specialty care system.

## **National Partnership for Pediatric to Adult Care Transition (NPPACT)**

The National Partnership for Pediatric to Adult Care Transition (NPPACT) is a multi-disciplinary group of stakeholders committed to advocating for federal programs, investments, and policies, which will help ensure smoother care transitions to support adults living with serious, life-threatening, and disabling conditions that were initially diagnosed, treated, and managed in childhood. Other common policy areas of interest could include training for and access to adult care providers, insurance coverage for adult care, supporting expanded telehealth flexibilities, and increasing funding for research into best practices.

### **To learn more about NPPACT, please contact:**

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