

How Title V supports: Children with Special Health Care Needs

Children with special health care needs (CSHCN) are those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally. According to the National Survey of Children's Health, as of 2018-2019, approximately 20.8% of children in Pennsylvania aged 0 to 17 are CSHCN. **Title V funds support more than 560,000 CSHCN annually, approximately 88% of all youth with special health care needs in the state.** Beginning in 2021, CSHCN health strategies will aim to advance Priority 3 and Priority 4 of the Title V Action Plan.

PRIORITY 3

Improve mental health, behavioral health, and developmental outcomes for children and youth with and without special health care needs

PRIORITY 4

Improve the percent of children and youth with special health care needs who receive care in a well-functioning system

Addressing priority health needs with evidence-based strategies



Specialty Care Services

Title V and matching state funds support patient-centered, team-based care and rehabilitation for children diagnosed with neuromuscular and orthopedic conditions, Cooley's Anemia, Cystic Fibrosis, Hemophilia, Sickle Cell, and Spina Bifida. Specialty Care Programs aim to promote comprehensive care and address barriers that prevent adherence to treatment plans. The state match also supports outreach and education for those with Epilepsy or Tourette Syndrome. Title V funds also support the use of telehealth to evaluate and diagnose children aged 12 to 18 months with autism.



Special Kids Network Helpline

The Special Kids Network phone line helps providers and families with children with special health care needs access local services and support. The network connects callers to resources in their communities and can provide information on education, transportation, insurance, transition, assistive devices, and more. The toll-free number is 1-800-986-4550 and is available Monday through Friday from 8:30AM to 4:00PM.



Youth Leadership and Development Training

In partnership with Pennsylvania's Family to Family Health Information Center (the Parent Education Advocacy Leadership Center), Title V supports youth leadership development among youth with disabilities and special health care needs across the state. The goal of youth leadership institutes is to help participating youth become self-sufficient and learn how to self-advocate.



Support for Families at Home

Established by the Philadelphia Department of Public Health in 2019, the Room2Breathe program utilizes community health workers to provide home-visiting services to families of children diagnosed with asthma. Services provided through the program include education, medication adherence, care coordination with primary care physicians, referrals to community resources, and environmental assessments to reduce in-home triggers. Families also receive assistance with pest management services and referrals for other identified needs around the social determinants of health.



Community to Home (C2H)

Community to Home is a home visiting program utilizing an evidence-based Community Health Worker model. The program focuses on rural, low-income families of CSHCN with a recent diagnosis as well as CSHCN who have recently moved to or are within the state. The goal is to empower families, develop care management plans, and connect families to needed resources.



Support for Children with Acquired Brain Injury

Title V supports the provision of rehabilitative and therapeutic services to individuals aged 18 through 25 with a non-traumatic acquired brain injury through its Acquired Brain Injury Program. Students with traumatic or non-traumatic acquired brain injury can also receive support through the Title V-funded BrainSTEPS program. BrainSTEPS assists students with transition back to school post-injury and supports schools in the development and implementation of educational plans.



Federally Qualified Health Center (FQHC) Program

The FQHC Program is designed to improve systems of care for CSHCN within participating FQHC health systems. In partnership with the Pennsylvania Association of Community Health Centers (PACHC), FQHCs are supported in implementing evidence-driven initiatives to target barriers and needs for CSHCN, then PACHC can operationalize successes across the FQHC system.

The Department of Health's Bureau of Family Health is the Title V Administrator in Pennsylvania.

For more information, e-mail RA-DHPATITLEV@pa.gov or visit our website:

<https://www.health.pa.gov/topics/Administrative/Pages/Title-V.aspx>