FAMILY VOICES®

. . . keeping families at the center of children's health care

TITLE V TIP SHEET: Title V – The State Program for CYSHCN

Perhaps your baby has a complicated health condition and you want to know about local programs. Or a teenage daughter with cystic fibrosis wants to move from her pediatrician to a physician who sees adults. Or your son with cerebral palsy seems to show signs of emotional problems. Or you know families who have children with special health care needs struggling to pay their medical bills. Is there an agency in every state for our children/youth (CYSHCN) with special health care needs and our families? Yes!

Which Children and Families Do Title V/CSHCN Programs Serve? The federal definition says: Children with special health care needs 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. This definition can include physical conditions, such as sickle cell disease or asthma. Or children with disabilities, such as cerebral palsy, down syndrome, autism, or who are technology dependent..

Title V is a Law. Under federal law every state has a Title V/CSHCN program to assist children with disabilities or chronic conditions and their families. The federal Social Security Act of 1989 requires states to" provide and promote family-centered community-based coordinated care…for children with special health care needs…and to facilitate the development of community-based systems of services." Funded with federal and state dollars, Title V programs help make sure that no child or youth with special health care needs goes without required services or programs.

Healthy People 2020, the health goals for the nation, states that there will be an increase in the number of states that have service systems for children/youth with special health care needs and that:

1. Families of children with special health care needs will partner in decision-making and be satisfied with services.
2. All children with special health care needs will have coordinated and comprehensive care in a Medical Home.
3. All families of children with special health care needs will have adequate private or public health insurance.
4. All children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so families can use them easily.
6. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including health care, work, and independence.

What Does a Title V/CSHCN Program Do? State Title V programs can, among other things:

- Identify children with special health care needs for managed-care organizations.
- Inform policymakers (legislators, Medicaid officials, schools) about our children and their needs.
- Make referrals to services, including health care providers, early childhood programs, Medicaid.
- Educate health and other professionals about our children and family-centered care.
- Provide services, such as specialty clinics, diagnostic screenings, care coordination. .
- Support local or state family peer support and information organizations.
- Develop state and local policies that assure quality health care and other programs.

To learn more about Title V visit the Family Voices website or connect with a Family Voices State Affiliate Organization (SAO) or a Family-to-Family Health Information Center in your state.

Family Voices, Inc • 3701 San Mateo Blvd NE, Suite 103, Albuquerque, NM 87110
Phone: **505-872-4774** • Toll Free: **888-835-5669** • Fax: **505-872-4780**
www.familyvoices.org • **www.fv-ncfpp.org** • **www-fv-impact.org** • **http://www.fvkasa.org**