

NC Family to Family Health Information Center

"A beacon for families of children with special health care needs."

NC Family to Family Health Information Center
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Fact Sheet

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Public Health Programs 2 Title V

Title V was enacted in Congress in 1935 as part of the **Social Security Act (SSA)**. Its roots go back to the 1912 creation of the Children's Bureau. Title V is the only federal legislation dedicated to promoting and improving the health of our nation's mothers and children; its goals remain consistent with those of its predecessor: "To serve all children, to try to work out standards of care and protection which shall give to every child fair chance in the world."

The Title V legislation authorized the creation of the Maternal and Child Health programs, thereby providing the foundation and structure needed to meet the nation's goals for healthy mothers and children.

Since its beginning, Title V has undergone many changes with the most significant being the conversion in 1981 to a block grant program as part of the **Omnibus Budget Reconciliation Act (OBRA '81)**. OBRA '81 consolidated Title V with five related programs:

- Supplemental Security Income (SSI) for children with disabilities.
- Lead based paint poisoning prevention programs.
- Genetic disease programs.
- Sudden infant death syndrome programs.
- Adolescent pregnancy grants.

The 1981 legislation gave states more freedom in determining how to use federal funds, allowing them to self-direct money to identified maternal and child health needs. Amendments made in 1989 to OBRA provided stricter rules for application and reporting requirements for states applying for Title V block grants.

Children with special health care needs (CSHCN) are defined by the federal government as: "...those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions 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, downs syndrome, autism, or who are technology dependent.

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. Like Medicaid, Title V is a federal/state-

The Family to Family Health Information Center is a Program of The Exceptional Children's Assistance Center (ECAC) and is affiliated with Family Voices of North Carolina. This fact sheet was developed with funding from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs. The NC Family to Family Health Information Center operates under the auspices of grant # H84MC08000.

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matching program. For every \$4 provided by the federal government, \$3 must be matched through state funds.

The health goals for the nation, Healthy People 2010, states that there will be an increase in the number of states that have service systems for children 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.

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.

Under the law, Title V can bill patients/families for services provided using a sliding fee scale based on income. Most services are free of charge, unless the patient has Medicaid or private insurance. There is a recent requirement that applicants denied **SSI** be referred to Title V.

For more information visit: <http://www.familyvoices.org> or <https://perfddata.hrsa.gov/mchb/mchreports>

Source: Family Voices Fact Sheet: Title V of the Social Security Act/SLAITS Survey
Title V: The State Program For Children and Youth with Special Health Care Needs (CYSHCN)
Maternal and Child Health Bureau Title V History